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of Health



Public Health  
England

**NHS**  
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# Improving Outcomes: A Strategy for Cancer

Fourth Annual Report

December 2014

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# A Strategy for Cancer

## Fourth Annual Report

**Prepared by**

Department of Health, Public Health England and NHS England

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# Foreword

In *Improving Outcomes: A Strategy for Cancer*, published in 2011, the Government set an ambition to save an additional 5,000 lives per year from cancer by 2015. Our strategy invested £750m in improving cancer services, including £450m in raising awareness and achieving earlier diagnosis. Although the final figures won't be known for some time, projections in this report show we could be on course to double our ambition and save 10,000 additional lives per year over this period. However, there is still more to do. This fourth annual report on the Strategy highlights not only where we have made great improvements, but also those areas where we must continue to push for progress.



Tackling cancer starts with prevention, and this is why I was pleased to see that prevention was put at the heart of NHS England's *Five Year Forward View*. The successful roll out of the HPV vaccination programme will protect many of our young women from cervical cancer. The lowest ever smoking rates, including in children, show that our first smoke-free generation could be in sight. However, there is still more to do to address the wider lifestyle risks for cancer and a wide range of long-term conditions. For example, we know we need to do much more to reduce the levels of obesity and get everybody active every day. I want to encourage the cancer charities, who have achieved so much in improving cancer outcomes, to focus their considerable campaigning clout on preventing cancer as well as curing it.

We know that the earlier people are diagnosed with cancer the more likely they are to survive. This is why we have invested over £450m in achieving earlier diagnosis and raising awareness of cancer symptoms. This investment has brought extremely encouraging results through our award winning *Be Clear on Cancer* campaigns and the successful roll-out of additions to the national screening programmes such as Bowel Scope Screening. We must continue to tackle late diagnoses. In this report we estimate that if the proportion of cancers diagnosed at stages 1 and 2 were increased by 10%, between 7,000 and 9,000 more people per year would survive their cancer for five years. However, a quarter of people are still diagnosed through emergency routes – tackling this will mean turning our focus increasingly onto hard to diagnose cancers, where survival rates have remained stubbornly unchanged.

Performance against waiting times has remained broadly stable, despite a huge increase in referrals, including 51% more urgent GP referrals for suspected cancer than in 2009/10. However, there have been some strains on performance against the 62-day standard for urgent GP referral to treatment. Along with the NHS, we have put clear plans in place to ensure the high standards that people rightly expect are maintained.

Further, we have put an additional £160m into the Cancer Drugs Fund, allowing more patients to access the drugs their doctors think they need, and the proportion of patients receiving advanced radiotherapy treatments continues to rise. Despite this, we recognise that there is still more to do to keep up with the latest treatment development, particularly in radiotherapy and molecular diagnostics. It is positive that the experiences of cancer patients continue to improve,

with 89% of patients rating their care as “excellent” or “very good”. However, we want all patients to have the best possible experience of their care and we must keep the focus on areas of improvement.

Finally, I would like to thank all of those, and in particular frontline NHS staff, who have worked so hard towards delivering this strategy. The goal remains simple but so precious, more lives saved from cancer.

A handwritten signature in black ink that reads "Jane Ellison". The signature is written in a cursive style with a horizontal line underneath.

**Jane Ellison MP**  
**Parliamentary Under-Secretary of State – Public Health**  
**Department of Health**

# Introduction

When *Improving Outcomes: a Strategy for Cancer* (IOSC) was published in January 2011, the Government committed to produce annual reports on progress on its implementation. We are very pleased to be publishing a joint Department of Health (DH), Public Health England (PHE) and NHS England report on progress in improving cancer outcomes in England.

We are delighted to be able to report this year that, for the first time, we have estimates of how many additional lives may have been saved against our ambition of saving an additional 5,000 lives a year by 2014/15, to halve the gap between the survival estimates in England and those in the best countries in Europe. Making these estimates has been challenging, and there are a number of caveats. However, using the latest survival estimates and assuming incidence is constant, we estimate that on average between 6,500 and 17,000 more patients per year diagnosed from 2011-2015 will survive cancer for five years compared to those diagnosed from 2006-2010. This is a projection and unfortunately cannot tell us anything about improvements relative to the best countries in Europe. We also would not claim that all the improvement is down to actions set out in the IOSC, but we believe that actions set out in that Strategy have had a significant impact on cancer survival in this country – and will continue to do so.

The main focus of IOSC was around improving cancer survival through earlier diagnosis of cancer and improved access to the best possible treatment. In the last year we have seen significant progress on:

- cancer screening, particularly achieving the commitment of 30% of Bowel Scope Screening centres operational by 31 March 2014
- the award winning Be Clear on Cancer campaigns, where we are starting to see significant evidence of their effectiveness
- further support for GPs in referring patients appropriately, for example, the use of Macmillan Cancer Support's Clinical Decision Support Tool in over 1,000 GP practices, and the expansion of the Cancer Research UK GP Engagement Programme
- ensuring better access for all to the best possible treatment, particularly in access to more precise forms of radiotherapy, with 35% of radiotherapy treatment now given by Intensity Modulated Radiotherapy against a standard of 24%
- further improvements in many of the responses to the questions in the Cancer Patient Experience Survey, showing more patients are reporting a better experience
- significant developments in the collection of and reporting on new datasets and the analysis of information, to drive improvements and to inform patients.

But we know there is much more to do to maximise the scope to save lives, including improving patient outcomes for rarer cancers, preventing cancers developing in the first place, modernisation of cancer screening, early diagnosis of symptomatic cancers, improved access to treatment and better care for cancer patients and survivors. Work continues in all these areas, especially:

- tackling the “lifestyle” factors, particularly smoking, which are responsible for over a third of cancers

- building on the success of the *Be Clear on Cancer* campaigns, with PHE committed to running new campaigns, such as the oesophago-gastric campaign in early 2015
- focusing on achieving cancer waiting times standards, particularly the 62 day referral to treatment standard that has recently been missed, and taking robust action when these are not met, such as NHS England setting up its cancer waiting times taskforce
- working with a range of partners to ensure there is sufficient diagnostic capacity to enable earlier diagnosis of cancers, particularly endoscopy capacity to meet the needs of the bowel screening programme and of symptomatic patients
- tackling variations in access to treatment by improving the data available, and looking at how we can provide the most up-to-date treatments as soon as possible
- continuing to improve services for cancer survivors, such as the cancer survivorship recovery package based on Macmillan Cancer Support's electronic holistic needs assessment, and promoting physical activity in cancer survivors.

Work also continues on improving end of life care for cancer patients.

Finally, there continues to be a need to tackle inequalities in access to cancer services and outcomes for patients. IOSC made clear that the ambition to save an additional 5,000 lives every year by 2014/15 could not be met without narrowing this equalities gap. Good progress has been made, such as:

- targeted interventions to certain groups in the *Be Clear on Cancer* campaigns, such as the campaign on breast cancer in women over 70 and the recent local campaign on prostate cancer in black men in London
- trying innovative interventions to improve uptake of cancer screening, particularly amongst disadvantaged groups where screening rates are lower
- keeping a focus on the treatment of older patients, with the launch of NHS England's *Older People and Cancer* project
- NHS Improving Quality's project pairing trusts with high levels of patient experience with trusts that have the potential to improve their patient experience
- the publication of the National Cancer Intelligence Network's second annual *Cancer and equality groups: key metrics*, highlighting improvements that have been made in staging and trusts reporting ethnic group.

We hope this report shows the progress made against the actions set out in the original Strategy and our joint continued commitment to improving cancer outcomes in England



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# 1. The scale of the cancer challenge

## Introduction

- 1.1. Since the publication of *Improving Outcomes: A Strategy for Cancer* (IOSC), progress has been made. Cancer survival estimates have continued to increase, and mortality rates have continued to fall. Incidence rates have begun – in some cases – to stabilise in recent years. However, cancer is the nation’s biggest killer, and still poses huge challenges for the NHS and Public Health services. Although we have seen some significant successes, there is still much more to be done. Over the course of this report we will update on the many achievements of the last year, as well as updating on areas of work still in progress.
- 1.2. In this first chapter, we assess the progress we have made since 2010 and lay out the scale of the challenge that we continue to face. We provide some brief background information about incidence, mortality, survival and spend, as well as an assessment of progress against our target to save an additional 5,000 lives per year.
- 1.3. Chapter 2 then sets out the progress that we have made in the collection and use of data, and how that is supporting patients and services to improve outcomes.
- 1.4. As in previous reports, the subsequent three chapters follow the patient pathway, focusing on prevention and early diagnosis, treatment, patient experience and survivorship, assessing progress against the improvements set out in IOSC.

## Incidence, mortality and survival

### Incidence trends

- 1.5. The 281,000 new cases of cancer registered in England in 2012 (143,000 in males and 138,000 in females) equate to an age-standardised rate of around 668 (in 2012, 665 in 2011) and 530 (in 2012, 529 in 2011) cases per 100,000 people for men and women respectively.<sup>1</sup> The number of registrations has increased by around 4,300 for males and 2,600 for females when compared with 2011. Breast, lung, colorectal and prostate cancers continue to account for over half of newly diagnosed cases of cancer in England.
- 1.6. 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, this rise in incidence has been slower than in previous years, in particular for females; between 2002-04 and 2009-11, the age-standardised incidence rate in England increased by 4% in males and 6% in females.
- 1.7. 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

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<sup>1</sup> 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.

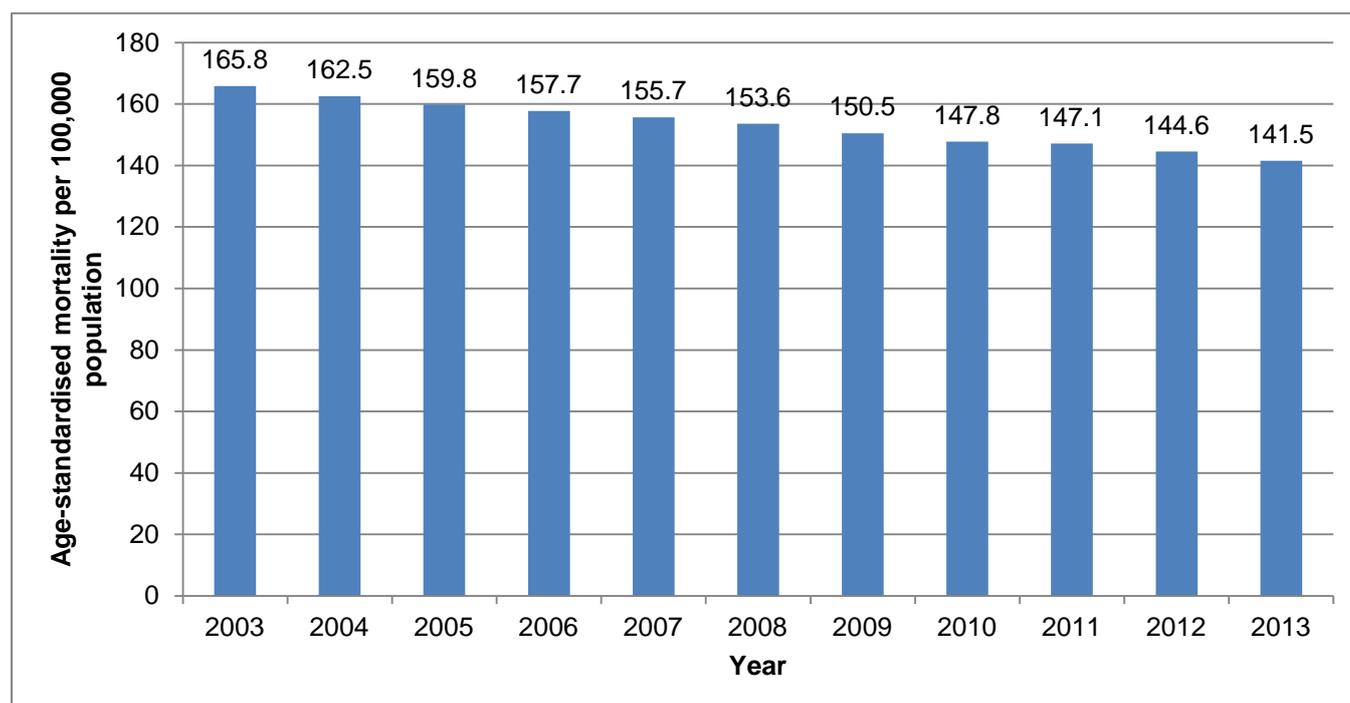
<http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/index.html>

diagnosed in those aged 75 or over. Between 2002-04 and 2009-11 age-standardised cancer incidence rates in those aged 75 and over in England were relatively stable in males, and increased by 8% in females. Over the same period, age-specific 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.

## Mortality trends

- 1.8. Office for National Statistics (ONS) mortality statistics show that cancers<sup>2</sup> were the broad disease group which had the largest percentage of deaths registered in 2013 in England, accounting for 29% of all deaths.<sup>3</sup> As in 2012, in 2013 there were around 133,000 deaths at all ages in England where the underlying cause was cancer; 70,500 males and 62,500 females.
- 1.9. Changes in mortality rates reflect changes in both incidence and survival. Over the last decade, under 75 mortality rates from cancer in England decreased significantly. The most recent data from the NHS Outcomes Framework<sup>4</sup> showed that the age-standardised cancer mortality rate (ages under 75) was 141.5 deaths per 100,000 population<sup>5</sup> in 2013, a decrease of 15% since 2003.

**Figure 1 Trend in cancer mortality, ages under 75, in England**



<sup>2</sup> 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)

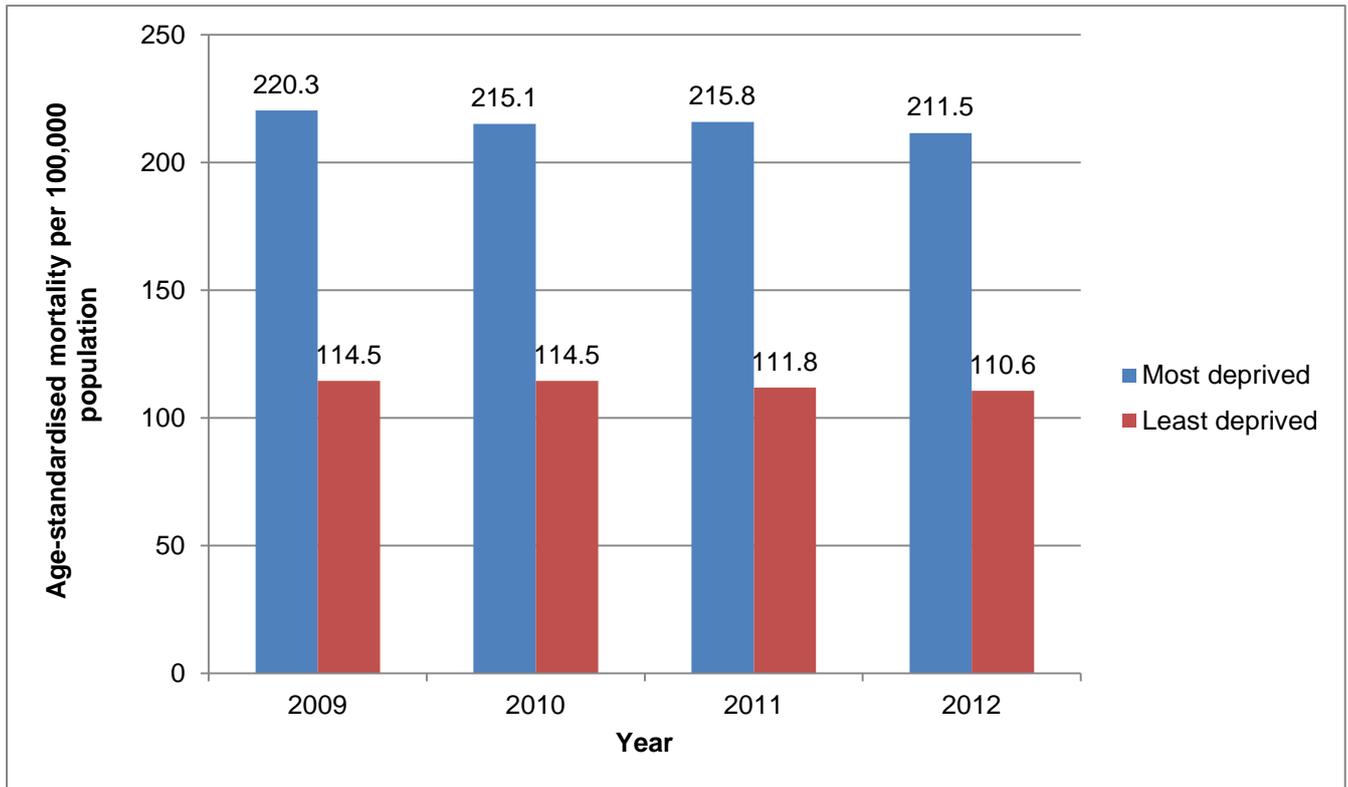
<sup>3</sup> ONS Death Statistics for England only

<sup>4</sup> Data taken from HSCIC indicator portal: <https://indicators.ic.nhs.uk/webview/>

<sup>5</sup> The standard population used for this standardisation has been updated in the last year to take account of changes in demography. Age-standardised mortality figures released this year therefore appear higher than in previous years, however the figures are not comparable.

- 1.10. Cancer mortality rates (ages under 75) have decreased in both more and less deprived areas, but there remains a clear social gradient in cancer mortality, with more deprived areas experiencing higher mortality rates than less deprived areas. In 2012, the most deprived 10% of the population had an under 75 mortality rate from cancer nearly double that of the least deprived 10% of the population.

**Figure 2 Under 75 mortality rates from cancer for most and least deprived population deciles in England**



### Survival trends

- 1.11. As last year, five-year survival estimates for patients diagnosed with 21 common cancers have generally improved slightly or stayed the same during 2008-2012 compared to 2007-2011<sup>6</sup>. There were five exceptions for which survival decreased slightly in this year's data: bladder cancer (down from 49.1% to 48.0%) and Hodgkin lymphoma (86.0% to 85.7%) for women; thyroid cancer in both men (82.9% to 81.8%) and women (87.3% to 86.8%); testicular cancer (97.1% to 96.6%) and mesothelioma (6.4% to 6.3%) for men, although these changes are small and may be the product simply of year-on-year variation.
- 1.12. As in 2007-2011, five-year survival in 2008-2012 was over 80% for cancers of the breast (women), prostate, testis, thyroid gland, Hodgkin lymphoma and melanoma of skin. Net survival is often considerably lower among the elderly, even after adjusting for death from other causes.
- 1.13. Five-year survival in 2008-2012 for cancers of the brain, liver, lung, mesothelioma, oesophagus, pancreas and stomach were less than 22% for women and less than 19% for men. This group of seven cancers with poor survival stands well below the estimates

<sup>6</sup> <http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/index.html>

of other cancers, all of which have a five-year survival estimate of at least 45%. However, with the exception of mesothelioma in men which decreased by 0.1% and pancreatic cancer in women which remained unchanged, there was a small improvement since 2007-2011 for both sexes. The lowest five-year survival for both sexes is in pancreatic cancer (5.4% for both sexes).

- 1.14. The largest improvement in five-year net survival between 2007 to 2011 and 2008 to 2012 was for men and women diagnosed with myeloma (improvements of 3.9% and 4.6% respectively). In men, large improvements were also seen in leukaemia (up 2.5%) and Non-Hodgkin lymphoma (up 2.3%). For women, kidney cancer had the next largest improvement (1.9%). There were also general improving trends for one-year survival.
- 1.15. For the first time, in 2014 ONS also published short term predictions of one-year and five-year net survival for patients that would be diagnosed in 2013. For most cancers, the predicted survival for these patients is higher than for those diagnosed during 2008 to 2012. The only exceptions to the overall trend are for five-year survival in men with cancers of the larynx and thyroid gland.

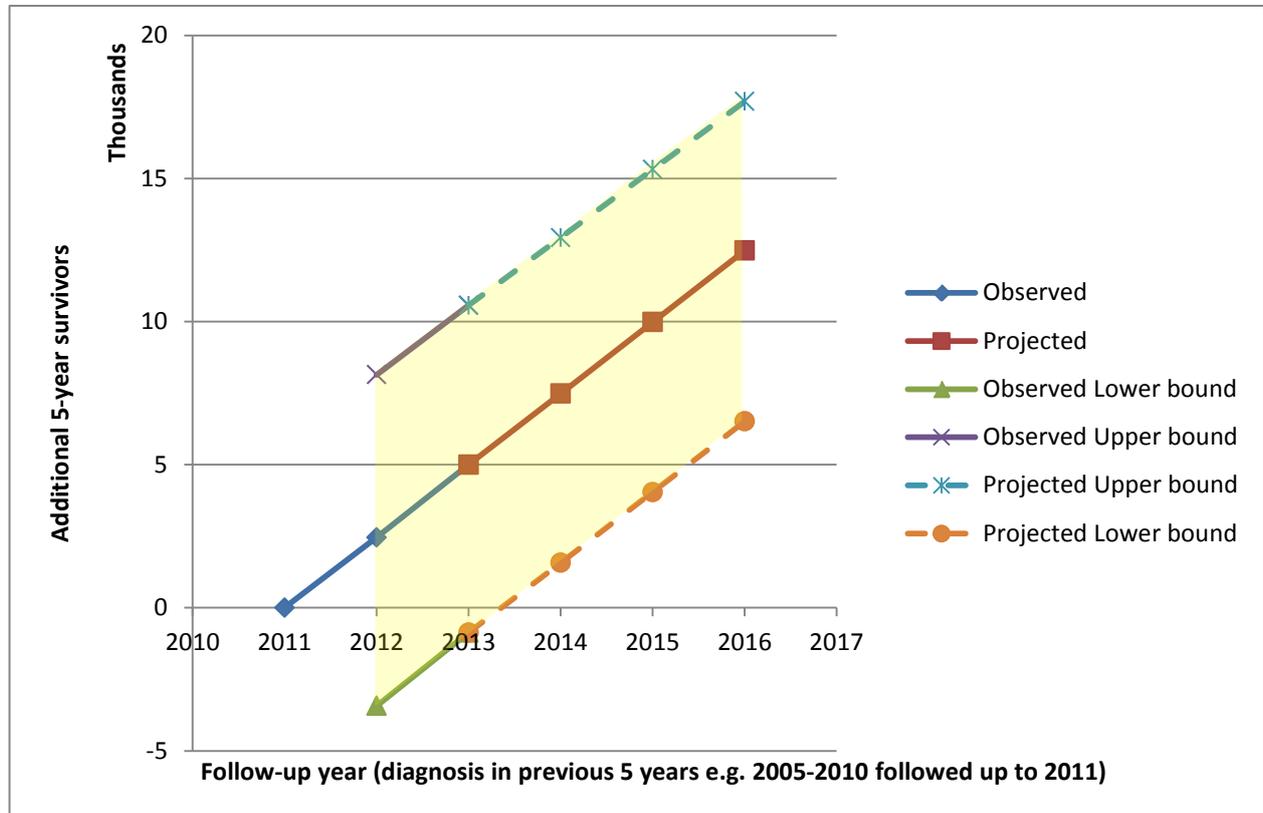
## Saving 5,000 lives

- 1.16. IOSC set an ambition to halve the gap in five-year cancer survival estimates between England and the best performing countries in Europe. At the time, we stated:
 

*“If England was to achieve cancer survival rates at the European average, then 5,000 lives would be saved every year. If England was to achieve cancer survival rates at the European best, then 10,000 lives would be saved every year. That is our challenge.”*
- 1.17. We therefore set an ambition to save an additional 5,000 lives per year by 2015, a goal that would stand as a proxy for halving the gap in survival between England and the countries in Europe with the highest cancer survival rates.
- 1.18. To produce as simple a comparison as possible, we compared the cohort of patients diagnosed immediately before the publication of IOSC (2006-2010) to the cohort projected to be diagnosed immediately after the publication of IOSC (2011-2015).
- 1.19. Clearly, we do not yet have survival data for the cohort of patients diagnosed during 2011-2015. Five-year survival estimates for each cancer and each age group were projected linearly to produce an estimate of the survival estimate expected for patients diagnosed from 2011-2015. Incidence for the cohort diagnosed in 2006-2010 was used throughout to avoid the effect of increasing incidence over time.
- 1.20. We estimate that on average 6,500-17,500 more patients per year, with a best estimate of 12,000 more patients per year, diagnosed from 2011-2015 will survive their cancer for five years than patients diagnosed from 2006-2010. This broad range arises because the margin of error given on the calculated survival estimates is comparable in size to the year-on-year increase in survival, and gives some context to the uncertainty inherent in this projection. We have not done any sensitivity testing ourselves on the analysis, but have used the confidence intervals calculated by the ONS.
- 1.21. This reflects a continuing trend in improving cancer survival estimates. Five-year survival for colorectal cancer improved from 54.8% for men diagnosed during 2006-2010, to 58.0% for men diagnosed from 2008-2012. Survival estimates for women diagnosed with colorectal cancer improved from 56.2% to 58.3% over the same span. Five-year survival estimates for women diagnosed with breast cancer have improved from 84.3%

to 85.8%. Although these improvements are mostly of the order of one to two percentage points per year, when applied to the large number of people diagnosed with cancer each year, they represent a significant improvement to the lives of thousands of people.

**Figure 3 Estimated additional annual five-year survivors**



- 1.22. Some caution is needed in the interpretation of these projections. There are three key caveats to make:
- the projections are indicative figures, based on the data currently available
  - this estimate can unfortunately tell us nothing about our improvement relative to the best countries in Europe, as the most recent available data for the rest of Europe runs up to 2007, and survival in Europe is likely to have improved significantly over this timeframe
  - we do not claim that all of the improvement in survival since 2011 is due to initiatives in IOSC.

### Spend on cancer

- 1.23. Expenditure on cancer has increased from £3.19 billion in 2003/4 to £5.68 billion in 2012/13.<sup>7</sup> This represents an increase of £680 million compared to 2011/12.
- 1.24. Commissioners have a range of resources, such as the Spend and Outcomes Tool<sup>8</sup> and the Clinical Commissioning Group Commissioning for Value packs<sup>9</sup>, that allow them to

<sup>7</sup> <http://www.england.nhs.uk/resources/resources-for-ccgs/prog-budgeting/>

explore the relationship between spend, activity and health outcomes to inform decision making. In October 2014 updated Commissioning for Value packs were published including three new pathways for lung, breast and colorectal cancer.

- 1.25. Large variation in expenditure levels between commissioners still exists – it is still the case that the highest spending commissioning organisation spends more than twice as much per person than the lowest spending organisation. However, it is unclear how much this variation can be explained by differences in the incidence and prevalence of patients with cancer and other factors.

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<sup>8</sup> <http://www.yhpho.org.uk/resource/view.aspx?RID=49488>

<sup>9</sup> <http://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/>

## 2. Improving our understanding of cancer – research and data

### Introduction

- 2.1. The importance of improving the quality of available data to drive improvements in patient outcomes has been emphasised in every Cancer Plan since the first national Cancer Plan in 2000. *Improving Outcomes: A Strategy for Cancer* (IOSC) renewed this commitment and took it further than ever before. Over the last year there have been key developments in the availability and analysis of cancer data, outlined in this chapter. However, in some cases data availability remains challenging and further work is needed.

### Outcomes Frameworks

#### NHS Outcomes Framework

- 2.2. The NHS Outcomes Framework (NHS OF) provides a national 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, 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 for the indicators were last published in November 2014.<sup>10</sup> Those particularly targeting cancer are the survival and mortality indicators within Domain 1. 2013 data published on 'Under 75 mortality rate from cancer' (indicator 1.4), released on 20 November 2014, showed further improvements as the rate again fell nationally. The Health & Social Care Information Centre (HSCIC) indicator portal provides data on this indicator both at national and local authority 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 2014/15 includes the following indicators relating to cancer survival in addition to the 'Under 75 mortality rate from cancer' indicator:
- 1.4i One-year survival from all cancers
  - 1.4ii Five-year survival from all cancers
  - 1.4iii One-year survival from breast, lung and colorectal cancer

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<sup>10</sup> <https://indicators.ic.nhs.uk/webview/>

- 1.4iv Five-year survival from breast, lung and colorectal cancer
  - 1.6ii Five-year survival from all cancers in children
- 2.6. The data for all of the above indicators was, as planned, published on the HSCIC indicator portal in February 2014, with indicators 1.4ii and 1.4iv being further updated in May 2014. The data for all of the above indicators has seen positive trends year-on-year. Data for all four indicators is due to be updated again in February 2015.
- 2.7. In addition, the HSCIC indicator portal provides time-series data for one- and five-year survival figures for breast, lung and colorectal cancer individually, which can be accessed from the 'Indicator data – previous methodology' section.<sup>11</sup>
- 2.8. We consulted on two new indicators concerning cancer for the refreshed NHS OF 2015/16. These were:
- One-year survival from cancers diagnosed at stages 1 and 2
  - Five-year survival from cancers diagnosed at stages 1 and 2
- 2.9. Such indicators, if adopted, would complement the Public Health Outcomes Framework (PHOF) indicator 2.19 – 'Cancer diagnosed at early stage'. The reasons for including these new indicators would be because indicators 1.4iii and 1.4iv are likely to suffer from lead time bias (the measure of survival can be improved by diagnosing earlier without postponing mortality) and length bias (the measure of survival can be improved by diagnosing a higher proportion of less aggressive cancers rather than postponing mortality). Thus, measuring survival at stages 1 and 2 would provide more complete information to facilitate an assessment of cancer survival outcomes.
- 2.10. If adopted, work to develop these indicators would be at an early stage. In 2014, Public Health England (PHE) published PHOF indicator 2.19 – 'Cancer diagnosed at early stage'. This indicator is labelled as 'Experimental Statistics' because of the variation in data quality: the indicator values primarily represent variation in completeness of staging information. Therefore, we would need to ensure that data on the stage of diagnosis and the link to survival is adequately robust at a national level if these indicators were to go live. Five-year survival data would not be available for some time.
- 2.11. The data for indicator 1.6ii (previously 1.6iii) – 'Five-year survival for all cancers in children' – containing statistics up until the end of 2011 was published on the HSCIC indicator portal on 25 February 2014. This indicator relates to children under 15 years old 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. The data for this indicator has seen positive trends year-on-year.

### Public Health Outcomes Framework

- 2.12. The PHOF and NHS OF share the 'Under 75 mortality rate from cancer' indicator, recognising the critical contributions that both the NHS and public health services can make to reducing 'preventable mortality'. In having a shared indicator, with joint

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<sup>11</sup><https://indicators.ic.nhs.uk/webview/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F172.16.9.26%3A80%2Fobj%2FStudy%2FP01658> and <https://indicators.ic.nhs.uk/webview/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F172.16.9.26%3A80%2Fobj%2FStudy%2FP01659>

accountability for delivery, PHE and NHS England have an incentive to work together on appropriate activity to achieve earlier diagnosis and these indicators will enable us to assess progress in improving cancer mortality. These are all showing movements in the desired downwards direction with continued improvements in both mortality and survival estimates for cancer in the latest period, 2013.

- 2.13. The PHOF indicator data on screening for breast and cervical cancers show movement in an unfavourable direction with slight reductions in coverage for both. The percentage coverage of 53 to 70 year old women eligible for breast screening has fallen slightly from 76.9% in the baseline year of 2010 to 75.9% in 2014. Similarly for cervical screening, the percentage coverage of eligible women receiving cervical screening has dropped from 75.5% in 2010 to 74.2% in 2014. This reflects a national and international long term trend showing a gradual fall in screening coverage over the last ten years. However, there is the potential to improve coverage rates, particularly amongst groups where coverage is low.
- 2.14. PHE is working with NHS England via the Public Health Section 7A agreement to develop a system of performance improvement through the use of performance floors, and strengthened governance for screening. *The Public Health England Marketing Strategy 2014 to 2017*<sup>12</sup>, published in July 2014, states that PHE will work with the national screening programme to trial mechanisms for improving uptake, particularly amongst disadvantaged groups. Cancer Research UK has undertaken work on improving bowel screening uptake in London, and the Department of Health Behavioural Insight team is developing a project on improving coverage in cervical screening. In addition, a major research study on increasing uptake of cervical screening in young women is due to report in 2015.
- 2.15. As mentioned above, in 2014 data for the existing indicator 2.19 – Cancer diagnosed at early stage were published as part of the PHOF for the first time. Whilst these data are still experimental and data quality can be further improved, their publication marks an exciting step forward in our understanding of cancer diagnosis.

### Clinical Commissioning Group (CCG) Outcomes Indicator Set

- 2.16. 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 OF.
- 2.17. The Indicator Set is intended as a benchmarking tool for CCGs to drive local improvement and set priorities. Indicators that had already been published included: under 75 mortality from cancer; one- and five-year survival from all cancers combined; and one- and five-year survival from breast, lung and colorectal cancers combined. New indicators added to the Indicator Set in 2014/15 include:
  - record of stage of cancer at diagnosis
  - percentage of cancers detected at stage 1 and 2
  - mortality from breast cancer in females

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<sup>12</sup> <https://www.gov.uk/government/publications/public-health-england-marketing-strategy-2014-to-2017>

2.18. Further consideration is being given to other relevant indicators.

## Intelligence to drive improvements and inform patients

### Cancers diagnosed through emergency routes

- 2.19. The National Cancer Intelligence Network (NCIN), operated by PHE continues to update and extend results from its *Routes to Diagnosis* project which has shown the different presentation routes for each cancer diagnosis. Results are available for all tumours diagnosed between 2006 and 2010 with breakdowns by age, sex, deprivation and ethnicity. Relative survival estimates show the differences in survival at time periods between one month and 36 months post diagnosis by route, with results available by sex, age and deprivation.
- 2.20. In January 2014 results were published showing breakdowns by Strategic Clinical Network and by CCG. Results also examined the different types of emergency presentations, showing that the majority originate from an Accident and Emergency department, with around 30% originating from an emergency GP referral.
- 2.21. NCIN published a poster at the NCIN Cancer Outcomes Conference in June 2014 looking at routes to diagnosis in more detail. *Routes to Diagnosis: Does it matter when or how a cancer is diagnosed?* showed information about the day of the week of presentation, survival estimates by cancer site, and trends over time.
- 2.22. For the period 2006 to 2010, the percentage of patients presenting through the screening and two week wait routes increased with time while the GP routine referral route remained stable. Emergency presentations and unknowns showed a decrease over time. These results are encouraging, as managed routes are associated with better survival compared to emergencies while the decrease in the percentage of unknowns represents an improvement in data quality.
- 2.23. The expanded datasets enable overall routes to be calculated for less common cancer sites, which previously had too few cases to produce meaningful results. In January 2014 NCIN published a data briefing looking at the results for Cancer of Unknown Primary (CUP), included for the first time, with breakdowns available by sex, age and deprivation. This showed that 57% of patients diagnosed with CUP presented as an emergency, which reflects the non-specific symptoms experienced by these patients. One-year survival for CUP for managed routes is above 24%, whereas for those who present as emergencies it is just 5%.

### Cancer survival by stage

- 2.24. NCIN published a report in August 2014 showing survival estimates by stage of disease for breast, colorectal, lung, ovarian and prostate cancers diagnosed in 2012. This report was possible due to improved collection of stage of disease in England, with completeness of over 80% in the sites examined.
- 2.25. For breast, colorectal and prostate cancers, age-standardised one-year relative survival is above 90% for stage 1 to 3 tumours with substantially lower survival for stage 4 tumours. For lung and ovarian cancers there is a marked decrease in survival with each increase in stage.
- 2.26. Age-specific results show differences that are statistically significant between stage 3 and stage 4 survival estimates for all age groups. For 15 to 59 year olds, 12-month survival estimates were more than 30% lower for colorectal and lung cancers at stage 4

compared to stage 3. Results from this study highlight the improvements in outcomes that can be made through earlier diagnosis of cancer.

- 2.27. The Department of Health and NHS England have together updated previous analysis to assess the improvement in five-year survival estimates that would be possible with a significant shift in stage at diagnosis. The headline results of this analysis were published in NHS England's *Five Year Forward View*<sup>13</sup> in October, and showed that a 10% increase in the proportion of cancers diagnosed at stages 1 and 2 may result in an improvement in five-year survival of between 3.3% and 4.4%, representing an additional 7,000-9,000 people surviving their cancer for at least five years. More information about this work can be found at Annex B.

## Equality and cancer

- 2.28. A second annual *Cancer and equality groups: key metrics* report<sup>14</sup> was published in June 2014. This report highlights the improvements that have been made in areas such as staging and trusts reporting ethnic group. The metrics contained within the 2014 report provide an overview of national trends, providing insight for commissioners and providers alike to enable further action.
- 2.29. The report showed that only 6% of episodes did not have an ethnicity assigned for cancer related inpatient stays in 2012. The quality of recording ethnicity has also improved in outpatient data, with completeness improving from 38% in 2010 episodes to 94% in 2012 episodes for all outpatient episodes related to cancer. This improvement in data completeness really makes a difference in helping to understand how cancer affects different ethnic groups and allows ethnicity to be a standard metric for cancer analysis outputs.
- 2.30. Risk factors for cancer, especially smoking, are strongly influenced by socio-economic determinants. In partnership with Cancer Research UK, NCIN published a report on cancer incidence and mortality by deprivation, *Cancer by Deprivation in England 1996-2011* in May 2014.<sup>15</sup> The report analysed 37 different cancer sites as well as 'all cancers combined'. The report found that there would be over 15,000 fewer cases of cancer in England each year if the rates for all deprivation quintiles were the same as the rates for the most deprived. Similarly, the report found that there was a yearly excess of 19,200 deaths from cancer due to the differences in cancer rates by deprivation quintile. A large proportion of both excess incidence (11,700 per year) and excess mortality (9,900 per year) are attributable to lung cancer.
- 2.31. To coincide with this annual report, NCIN is publishing a report on older people and cancer, in collaboration with multiple stakeholders and partners. The report summarised the evidence that currently exists on older people and cancer, supporting the National Clinical Director's 'call to action' on the issue in December 2013, and draws attention to where further evidence is needed. It highlights the contribution that improving services for older people affected by cancer could have on wider health outcomes, and draws attention to the increasing impact that older people affected by cancer will have on health service costs and outcomes.

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<sup>13</sup> <http://www.england.nhs.uk/ourwork/futurenhs/>

<sup>14</sup> [www.ncin.org.uk/view?rid=2697](http://www.ncin.org.uk/view?rid=2697)

<sup>15</sup> [http://www.ncin.org.uk/about\\_ncin/cancer\\_by\\_deprivation\\_in\\_england](http://www.ncin.org.uk/about_ncin/cancer_by_deprivation_in_england)

## Indicators and profiles

- 2.32. NCIN profiles provide a range of comparative information, and form an important part of the data available to support commissioners, with the Cancer Commissioning Toolkit (CCT) being the main entry point for commissioning information. The fourth version of the GP Profile for Cancer, updated for December 2013, will shortly be available to the public, as well as through the 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.
- 2.33. NCIN has a programme to provide Multi-Disciplinary Team (MDT) based service profiles across a range of cancer sites. Profiles for breast and colorectal cancer MDTs were published in March 2013 along with the first set of profiles for lung cancer MDTs. These were followed in September 2013 by the publication of profiles for head and neck, gynaecological and oesophagogastric cancers and sarcoma. Profiles for haematological, hepato-biliary, brain and central nervous system, urology and skin cancers are in preparation for publication in early 2015. The profiles for breast, lung and colorectal cancers were refreshed in March 2014, with the profile for lung cancer also being released into the public domain in March 2014. These profiles bring together a range of outcomes and process information to provide comparative information at acute trust or MDT level.
- 2.34. Service profiles promote a stronger focus on clinical issues by the National Peer Review Programme, in order to make reviews clinically relevant and to sustain the continued support and involvement of clinical staff. They also assist clinical teams to reflect on their own outcomes, and enable benchmarking against other services.
- 2.35. NCIN continues to work closely with the HSCIC to define and test the cancer related indicators for use in the 2015/16 CCG Outcomes Indicator Set, including where possible aligning with the PHOF and other relevant indicators.

## Survivorship data

- 2.36. As is now well established, around two million people are currently living in the UK with a cancer diagnosis, and this is projected to increase to four million by 2030. In partnership with Macmillan Cancer Support, NCIN is using national patient-level cancer datasets to describe this population including their characteristics and needs. There is little granular information about the cancer survivorship population, yet there are more people surviving cancer and living for longer.
- 2.37. As part of the Macmillan Cancer Support-NCIN partnership, two posters were published at the NCIN Cancer Outcomes Conference in June 2014 presenting 20 year prevalence data for specific groups of the population. Cancer prevalence is the number, or proportion, of people still alive on a given date who have been diagnosed with cancer in the past.
- 2.38. *Understanding the burden and characteristics of older people living with and beyond cancer across the UK* showed the number of older people that have been diagnosed and living with cancer, and demonstrates the variation in their characteristics and needs when analysed by the people's demographics, cancer type, locality and by different stages along their pathway.
- 2.39. *UK cancer survivorship: What the data tell us about the number of children, teenagers and young adults living with and beyond cancer* showed that children, teenagers and

young adult cancer survivors are most commonly been diagnosed with leukaemias and cancers of the central nervous system, including the brain.

- 2.40. *Routes from Diagnosis* is a programme of research performing retrospective analysis of almost 85,000 cancer patients' interactions with the NHS in England over seven years. Pairing analysis with clinical insight, it reveals significant variation in outcomes, survival and cost within and between cancer types. *Routes from Diagnosis* was developed by Macmillan Cancer Support in partnership with NCIN and Monitor Deloitte.
- 2.41. A report summarising the results of the first phase of the routes from diagnosis study was published in April 2014. It includes outcome pathways, survival estimates, inpatient costs and morbidities associated with breast cancer, lung cancer, prostate cancer and brain and central nervous system tumours.

### Cancer intelligence to inform commissioning

- 2.42. The CCT was developed to support commissioning of cancer services by providing a reservoir of cancer information from a variety of trusted sources. It is a one stop shop for cancer information covering the patient journey. There are two routes of entry – public view (open to all in line with the principles of open data) and NHS professional view (access controlled to ensure compliance with governance of data sharing of small numbers etc.). The CCT is updated quarterly with the latest nationally available data.
- 2.43. In 2014, NCIN updated the CCT to include the latest incidence and mortality data, one-year and five-year survival index estimates calculated by ONS, and staging data, as well as further implementing upgraded charting software to improve data visually and enhance user functionality.
- 2.44. In August 2014 Macmillan Cancer Support, in partnership with NCIN, launched the 'Local Cancer Intelligence' tool, designed to help commissioners understand the changing burden of cancer in their local area. This is an easy to use public facing tool that provides headline information on numbers, needs and experiences by CCG, including prevalence, incidence, mortality, survival, patient experience and routes to and from diagnosis. Cancer Research UK have also developed a 'Local Cancer Stats' tool, informed by NCIN analysis and including a broad range of cancer outcomes information at a local level.

### Cancer intelligence and clinical leadership

- 2.45. The NCIN's Site-Specific Clinical Reference Groups (SSCRGs) continue to deliver clinically-led analytical work programmes. These include a small number of analytical projects that contribute to improved patient outcomes, improved cancer services, and informed commissioning via reports, data briefings and journal articles. Data Briefings<sup>16</sup> are produced to accompany journal articles so that the key messages are fully accessible to the NHS and wider general public.
- 2.46. During 2014 the SSCRGs have produced 15 Data Briefings (two page reports with a key message supported by the main evidence), 13 in depth site-specific reports, ranging between analyses of data quality and completeness, to detailed investigations of specific cancers (e.g. uterine and sarcoma), and contributed to nine journal articles.

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<sup>16</sup> [http://www.ncin.org.uk/publications/data\\_briefings/](http://www.ncin.org.uk/publications/data_briefings/)

- 2.47. SSCRG membership is drawn from a range of stakeholders, including clinicians, patients, voluntary organisations, NHS England and the national cancer audit programme. Clinical representation is designed to mirror the range of specialities involved in the site-specific multi-disciplinary management of patients along their care pathway. Each of the 12 SSCRGs meet twice a year and hold an annual workshop aimed at clinical leads in MDTs, commissioners, and Clinical Nurse Specialists. In 2014 12 workshops were held, attended by nearly 700 clinicians from across the UK.

### Training for cancer intelligence staff

- 2.48. The NCIN and partners continue to support the open access *Understanding Cancer* online learning programme. This course provides a comprehensive accredited training programme for all NHS and public health non-clinical staff working with cancer. It has been aimed at those supporting MDTs and cancer registration staff but is also of particular benefit to research data staff and to analytical teams working with cancer.
- 2.49. The course now contains 40 modules covering a range of cancer types, as well as more general topics concerning cancer such as datasets and cancer registration, diagnostic tests, treatments and medical terminology. In 2014 the project team developed new modules for haematological cancers and sarcomas and are planning to develop modules on cancers affecting children, teenagers and young adults and cancers of unknown primary, as well as starting a two year review cycle to update the existing modules.
- 2.50. As at October 2014, over 3,000 people were registered on the *Understanding Cancer* course, and between them they have completed over 9,000 modules and over 38,000 individual sections. In a 2014 user survey the course was rated good to excellent by 98% of respondents and useful by 99%, with at least 95% rating both the course level and module length as “about right”.

### Office for Data Release (ODR)

- 2.51. PHE has a number of statutory responsibilities for the data and information it collects and generates, including to ensure that any data sharing complies with the data protection principles. The Office for Data Release (ODR) was established in January 2014 to provide a cross-agency service function to manage the release of explicitly identifiable or potentially identifiable data from PHE.
- 2.52. The ODR has focused significant resource into handling outstanding applications and determining asset-specific standard operating procedures. While the ODR continues to evolve, developing infrastructure and capacity remain key priorities. A central team has been established to respond to enquiries/applications, along with a dedicated mailbox and secure file transfer system.
- 2.53. The ODR’s core customers have been members of the cancer research community and NHS Trusts (returning data to the treating clinician). The majority of new contacts relate to applications for data from the research community to exploit cancer registration data or to utilise linked data as part of the Clinical Practice Research Datalink (CPRD) linkage scheme.
- 2.54. PHE is committed to ensuring that the public understands what happens to the information that PHE collects, generates and shares under the strict controls of the Data Protection Act 1998 and other associated controls. Following the August 2014 meeting of the Data Release Advisory Board, the ODR will now work towards publishing all

instances where explicitly or potentially identifiable data has been released for research, clinical audit and service design by the agency.

## Key datasets

### Cancer Outcomes and Services Dataset (COSD)

- 2.55. The Cancer Outcomes and Services Dataset (COSD – ROCR/OR/2142/FT6/001MAND) is designed to support consistency in data recording, data submission and outcomes analysis across NHS cancer services in England.
- 2.56. 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, with further site-specific clinical items mandated from July 2013 and site-specific pathology items (a subset of the Royal College of Pathologists datasets) from January 2014, making up the full dataset. There is a comprehensive user guide, detailing the phased implementation plan, available on the NCIN website.
- 2.57. During 2014, PHE's National Cancer Registration Service (NCRS) established a COSD conformance portal that allows clinical teams, service providers and commissioners to monitor the progress with the implementation of the COSD Information Standard across all NHS providers of cancer care in England. The portal allows the user to view multiple comparative conformance data levels across the whole of England by Strategic Clinical Network, by former Cancer Networks, by Service Provider and by MDT. The portal offers views of the timeliness and completeness of cancer data received from different hospital systems. There is a continued focus on monitoring the submission of stage data as well as several other key items such as performance status, Clinical Nurse Specialist contact and basis of diagnosis. The NCRS data liaison teams use the reports to highlight areas of action for cancer teams relating to their systems and processes for capturing and reporting data.
- 2.58. The conformance portal has also been developed to provide views of the data by CCG of residence and there are further plans in early 2015 to support conformance monitoring for a number of the national cancer audits. The NCRS will be working with the NCIN and its SSCRGs to explore how clinically relevant analysis of the data can be presented through the portal.
- 2.59. The leverage that the COSD standard has introduced, the launch of the conformance portal and the continuing direct liaison with Trust clinical teams has seen a huge improvement in the capture and reporting of cancer stage data.

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

- 2.60. The two-year implementation period for the SACT programme finished at the end of March 2014. The dataset covers the collection of treatment data on all adult solid tumours, haematology and paediatric chemotherapy and is mandated within NHS England's chemotherapy specification. All 147 Trusts providing chemotherapy are fully engaged with the programme and submitting data on a monthly basis.
- 2.61. PHE's 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.<sup>17</sup>

- 2.62. The SACT database contained treatment records of over 155,000 patients by July 2014 with details of over 680,000 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 have been developed including: 30, 60, 90 day post chemotherapy mortality in relation to specific regimens and patient sub groups; dosage patterns of individual drugs; and body surface area by sex and tumour group.
- 2.63. The CIU has established a data exchange between the SACT system and the National Cancer Registration Service. This data linkage allows the SACT system to access mortality and staging information that is vital to the analytical outputs for the CIU.

### Radiotherapy Dataset (RTDS)

- 2.64. Data on radiotherapy using the Radiotherapy Dataset (RTDS) have been collected, collated, analysed and reported for every English provider of radiotherapy services since April 2009 by the National Clinical Analysis and Specialised Applications Team (NATCANSAT). Version 4 of the RTDS includes teletherapy and brachytherapy.
- 2.65. The RTDS database contains millions of records including radiotherapy episodes and attendances and measures of treatment complexity. The database is used to generate an extensive range of interactive reports via the RTDS microsite. It is also used to support the NHS Quality Measures Dashboard and the NCIN CCT. NHS England monitors the progress of the use of Intensity Modulated Radiotherapy (IMRT) and the radiotherapy Quality, Improvement, Productivity and Prevention (QIPP) measures to ensure delivery of quality measures. The national average for IMRT is now 36% for England.
- 2.66. The National Radiotherapy Advisory Group has recommended that around 50% of cancer patients should receive radiotherapy at some time during their illness. At the time of publication, the actual proportion of cancer patients receiving radiotherapy was reported as 33%. In 2013, two key studies were undertaken to review of the evidence on access rates.<sup>18,19</sup> The studies concluded that this figure should be closer to 40.6% of cancer patients receiving radiotherapy at some time during their illness. In 2013, the access rate for patients accessing radiotherapy had risen to 37.9% as an England average.
- 2.67. Variation remains in the usage of linear accelerators (linacs) between centres. The usage rate across the five centres with the lowest usage in 2013-14 was 5,936 attendances per linac, while the usage rate in the five treatment centres with the highest usage was 8,995 attendances per linac. This variation may reflect a number of factors, such as differing equipment or referral behaviour. Maximising the efficiency of equipment usage is a key priority for radiotherapy centres.

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<sup>17</sup> [www.chemodataset.nhs.uk](http://www.chemodataset.nhs.uk)

<sup>18</sup> [The role of radiotherapy in cancer treatment: estimating optimal utilization from a review of evidence-based clinical guidelines](#). Delaney GP et al, Cancer 2005, 104:1129-37

<sup>19</sup> [Radiotherapy demand and activity in England 2006-2020](#), Round CE et al. Clin Oncol 2013, 25:522-30

- 2.68. Responsibility for collating and analysing RTDS is being transferred from NATCANSAT to NCRS. Data transfer between the provider trusts and the NCRS is included in data sharing and partnership agreements that are already in place for other cancer datasets.

### Recurrent and metastatic breast cancer data collection

- 2.69. The collection of robust breast cancer recurrence data remains high on the NCIN's agenda. From 1 April 2012, all NHS Trusts should have been recording recurrent and metastatic breast cancer patients. The information collected should be recorded by the Multi-Disciplinary Teams and picked up in the Cancer Waiting Times (CWT) system.
- 2.70. Initial analysis of the CWT data based on referrals to hospital between 1 April 2012 and March 2013 shows that 7,176 patients were diagnosed or treated for recurrent breast cancer in England. However, the ratio of recurrent breast cancers treated or diagnosed, compared to primary cancers, varied significantly by NHS Trust from 0.004 to 0.676. These analyses require updating with more recent CWT data to establish if this discrepancy has corrected with time.
- 2.71. The NCIN, Macmillan Cancer Support and the PHE Knowledge and Intelligence Teams are also working collaboratively on an algorithm to establish treatment patterns for patients with breast cancer, which will detect patients with recurrent breast cancer. Results from this collaborative piece of work should be available in 2015.

### Diagnostic Imaging Dataset

- 2.72. The Diagnostic Imaging Dataset (DID) contains detailed data on diagnostic imaging tests for NHS patients in England, compiled monthly since April 2012. It includes estimates of GP usage of direct access to key diagnostics tests for cancer, fulfilling a specific commitment of the original strategy.
- 2.73. The results are published monthly by NHS England and compiled into an annual summary report.<sup>20</sup> Commissioners and providers may access the DID via NHS iView<sup>21</sup>, to assist their planning.
- 2.74. Low use and delays in the delivery of diagnostic tests may lead to problems in diagnosing cancer earlier. A project is underway to explore whether GP direct access to four key tests outlined in IOSC has any impact on cancer patient outcomes, at this stage using proxy outcomes in the absence of timely survival data. The tests are chest X-ray, brain MRI, non-obstetric ultrasound of the abdomen and/or pelvis and colonoscopy/flexible sigmoidoscopy/CT virtual colonoscopy.

### The National Cancer Registration Service

- 2.75. The NCRS continues to make good progress with data collection. Staging completeness for cases of the major cancer types used in the International Cancer Benchmarking Partnership (ICBP, breast, bowel, lung and ovarian) and prostate cancer diagnosed in 2012 exceeded 80% nationally for the first time. On the basis of this high quality data, PHE were able to publish one-year, stage-specific survival estimates for patients diagnosed with these cancers for the whole of England in September 2014. This is a remarkable achievement and places England amongst the highest performing cancer data collection systems in the world.

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<sup>20</sup> <http://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/>

<sup>21</sup> <https://iview.hscic.gov.uk/>

- 2.76. The quality and richness of the data in the NCRS also continues to improve. The Healthcare Quality Improvement Partnership (HQIP)-funded National Prostate Cancer Audit started data collection in April and urology teams across the country submit the audit data directly from their MDT meetings to the NCRS, increasing timeliness and reducing the burden of front-line data collection. Meanwhile, work with genetic and molecular testing laboratories has delivered a wide range of important tumour specific molecular test results.
- 2.77. The NCRS continue to work hard to engage and inform patients. The patient portal developed in partnership with Cancer Research UK and the BrainsTrust is now live and allows patients access to all the data held on them, should they wish to do so. With the help of Cancer Research UK and patient focus groups we have improved our patient leaflet and created an online booklet for those who wish to know more.
- 2.78. There are still challenges for the NCRS. Further improvements to the timeliness and completeness of data are planned for next year. By the end of 2014, stage data for all stageable tumours of the eleven most common cancer sites should be available, which, taken together, will cover almost 80% of all cancers diagnosed in England (excluding non-melanoma skin cancers). From January, the richer COSD data will begin to be processed on all new cases. In March, the first of the 2015 cases will begin to be processed so that these will be available to clinical teams and others who need the information within a few months of diagnosis through new online data feedback systems. In May, staging profiles for England in the PHOF will be published.

### International Cancer Benchmarking Partnership (ICBP)

- 2.79. The ICBP, project managed by Cancer Research UK, has previously established that cancer survival estimates for England continue to lag behind the best performing countries in the partnership, and the partnership team has continued to investigate why these differences exist.
- 2.80. To date, eleven peer reviewed papers have been published in high quality journals presenting the results of the core international analyses; these papers have been cited over 370 times.<sup>22</sup> Further publications are in the pipeline. The results of these studies – and their impact on policy and practice in the UK and internationally – have been presented at plenary sessions in major conferences including the NCIN Cancer Outcomes Conference, 9-10 June 2014. The Union of International Cancer Control's World Cancer Congress in Melbourne, Australia, 3-6 December 2014 also showcased ICBP to share global lessons from the partnership.
- 2.81. The partnership's results<sup>23,24,25,26,27,28,29,30,31</sup> have provided evidence to help inform an early diagnosis summit in England in June 2014, hosted in partnership between the

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<sup>22</sup> Google scholar, accessed 12 September 2014

<sup>23</sup> [Breast cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK, 2000-2007: a population-based study](#), Walters S et al. Br J Cancer 2013, 108:1195-1208

<sup>24</sup> [Stage at diagnosis and ovarian cancer survival: Evidence from the International Cancer Benchmarking Partnership](#), Maringe C et al. Gynecologic Oncology 2012, 127:75-82

<sup>25</sup> [Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom: a population-based study, 2004-2007](#), Walters S et al. Thorax 2013. 0:1-14

National Clinical Director for Cancer and Cancer Research UK, and subsequent work on improving cancer diagnostic pathways across England. ICBP findings have also confirmed the importance of existing elements of *Be Clear on Cancer* campaigns which include calls to ‘go and see your GP’ and ‘tell your doctor’, and target messages at older age groups. These address barriers cited more frequently by members of the general public in the UK compared to other countries.<sup>28,29</sup>

- 2.82. ICBP studies<sup>23,24,25,26</sup> highlight that having complete, standardised and routinely collected information about stage at diagnosis is extremely important in aiding our understanding of the reasons international cancer survival variations exist, including explaining the role of early diagnosis and access to optimal treatments. These findings reinforce the importance of efforts already underway in England to improve and standardise the timely collection of data, including stage at diagnosis.
- 2.83. ICBP research into the role of primary care in cancer diagnosis, using patient scenarios to attempt to identify differences between countries in how GPs manage patients with symptoms, has been submitted for publication. The study also looked at whether there were differences between countries in ease of access to specialist advice as well as the availability of direct access to, and the length of waiting times for, diagnostic tests.
- 2.84. The first robust international comparison of time from first symptom(s) until diagnosis and start of treatment for cancer patients is progressing well, with over 8,000 patient responses received so far across ten jurisdictions. This novel study is looking at whether spending more time on the pathway to diagnosis contributes to poorer patient outcomes. It will also describe and compare the various routes by which patients are diagnosed, including via screening, hospital presentations or symptomatic presentation to a GP, to provide insights for actions to reduce delays. The results of the analysis will be presented in a series of international comparisons throughout 2015.
- 2.85. The ICBP is also exploring the extent to which comorbidities (whether patients are more likely to be living with one or more health condition in some partner jurisdictions than in others) might impact on observed differences in survival. The study is focusing on lung cancer patients initially and aims to use linked data from hospitals and cancer registries to quantify the levels of comorbidity across jurisdictions and investigate the relationship between comorbidity and the surgical treatment, short-term mortality and long-term survival of patients.

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<sup>26</sup> [Stage at diagnosis and colorectal cancer survival in six-high income countries: a population-based study of patients diagnosed during 2000-7](#), Maringe C et al. *Acta Oncologica* 2013, 52(5):919-932

<sup>27</sup> [Comparability of stage data in cancer registries in six countries: Lessons from the International Cancer Benchmarking Partnership](#) Walters S et al. *International Journal of Cancer* 2013, 132(3):676-85

<sup>28</sup> [Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK \(the International Cancer Benchmarking Partnership\): do they contribute to differences in cancer survival?](#) Forbes LJL et al. *British Journal of Cancer* 2013, 108(2):292-300

<sup>29</sup> [An international measure of awareness and beliefs about cancer: development and testing of the ABC](#), Simon AE et al. 2012. *BMJ Open*, 2:e001758.

<sup>30</sup> [Development of a survey instrument to investigate the primary care factors related to differences in cancer diagnosis between international jurisdictions](#), Rose PW et al., *BMC Family Practice* 2014, 15:122.

<sup>31</sup> [How might healthcare systems influence speed of cancer diagnosis: A narrative review](#), Brown S et al. *Social Science and Medicine* 2014, 116:56-63

- 2.86. A further study is exploring how differences in cancer registry practices between countries might affect international cancer survival analyses, particularly in the first few months after diagnosis. A simulation model has been developed and users can adjust a variety of key parameters including date of diagnosis, tumour site and the proportions of patients diagnosed at a given stage and measure any impact on one-year cancer survival.

## Research

- 2.87. Health research is a major Government priority and public funders continue to invest in a wide range of research into the causes of cancer, prevention, screening, diagnosis, therapy and the organisation and delivery of services. The National Institute for Health Research (NIHR) invested £130 million in cancer research in 2013/14.
- 2.88. The NIHR Clinical Research Network (CRN) is undergoing transition to a simpler structure in order to become more streamlined and efficient. The transitioned Network will be able to deliver research studies faster, and to give more patients, including cancer patients, access to innovative treatments. In 2013/14, the CRN recruited nearly 80,000 participants to cancer studies.
- 2.89. The UK Health Departments and Cancer Research UK are jointly funding a network of 18 Experimental Cancer Medicine Centres (ECMCs) across the UK investing a total of £35 million in the second five-year period (2012 to 2017). Fourteen of these ECMCs are in England. The aim is to drive the discovery and early-phase clinical testing of new anti-cancer treatments and biomarkers.
- 2.90. A huge number of developments continue within cancer research. Two exciting examples are FOCUS4 and an ovarian cancer test called ADNEX. The FOCUS4 trial programme is testing new cancer drugs in patients with different subtypes of advanced and incurable bowel cancer and opened to recruitment in January 2014. FOCUS4 is jointly funded by the Efficacy and Mechanism Evaluation Programme and Cancer Research UK and involves collaboration between the CRN, ECMCs and the Medical Research Council Clinical Trials Unit. The trial programme employs an innovative trial design that allows a wide range of patients to take part depending on the molecular make up of their particular cancer. This trial design, involving molecular cohorts, maximises the possibility of detecting promising new treatments or rejecting unsuccessful ones.
- 2.91. An international team led by the NIHR Imperial Biomedical Research Centre and KU Leuven, Belgium, has devised a new test to help doctors diagnose ovarian tumours and choose the most appropriate treatment. The test, called ADNEX, can discriminate between benign and malignant tumours, and identify different types of malignant tumour, with a high degree of accuracy. The ADNEX test is available online and in mobile apps.
- 2.92. 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 January 2014, the NCRI published an analysis of funding of children's cancer research based on 2008 data from the International Cancer Research Partnership portfolio.

## Information and research

- 2.93. As part of the ongoing relationship between NCIN and UK Biobank, the Outcomes Adjudication and Longitudinal Follow Up Group has been used to report on the linkage activity to support cancer outcomes adjudication within the cohort.

- 2.94. UK Biobank and the NCIN are talking to others, such as the Farr Institute, about how they may best exploit the data held by the NCIN and work collaboratively to explore methodological issues (such as imputation of missing data) involved with the handling and interpretation of 'big' data.
- 2.95. Other disease-specific adjudication groups are also interested in the value that could be derived from working with the intelligence networks to improve the quality of data submitted by our NHS partners and ultimately made available to third parties for research.
- 2.96. Unfortunately, there has not been significant progress linking NCRS data to clinical trials data, although this remains a priority for 2015/16.

## 3. Prevention and early diagnosis

### Introduction

- 3.1. *Improving Outcomes: A Strategy for Cancer* (IOSC) set out a series of priorities for prevention and early diagnosis, as the core of our work to improve cancer outcomes. This chapter provides updates on a wide range of initiatives, including our major prevention programmes focusing on vaccination and tobacco use, our successful *Be Clear on Cancer* awareness campaigns, and the successes and challenges facing the cancer screening programmes.
- 3.2. In March 2013, the Department of Health published *Living Well for Longer: a Call to Action on Avoidable Premature Mortality*<sup>32</sup>, outlining 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. In April 2014, the Department published *Living Well for Longer: National Support for Local Action to Reduce Premature Avoidable Mortality*<sup>33</sup>, bringing together the national actions being taken by the Department of Health and wider Government, NHS England and Public Health England (PHE), to prevent, diagnosis and treat the five major causes of avoidable death. NHS England, in its *Five Year Forward View* also placed a clear focus on “getting serious about prevention.”

### Prevention

#### Human papillomavirus (HPV) vaccination

- 3.3. PHE’s final estimates of HPV vaccine coverage in England for 2013/14 (published December 2014) show that routine HPV immunisation coverage in England for females aged 12 to 13 years in school year 8 remains high and that national coverage rates are similar to the equivalent reported rates for females receiving routine HPV immunisation in 2012/13. In 2013/14, 86.7% of girls aged 12 to 13 years had completed their course of three HPV immunisations by the end of the school year (86.1% in 2012/13); 89.8% had received doses one and two (89.6% in 2012/13); and, 91.1% had received one dose (90.9% in 2012/13). These are some of the highest HPV vaccine uptake figures in the world.
- 3.4. The Joint Committee on Vaccination and Immunisation (JCVI), the Government’s independent expert advisers on immunisation matters, has been reviewing the case for HPV vaccination for men who sex with men (MSM) in sexual health services and also the potential extension of the programme to include adolescent boys. For MSM, JCVI has considered a cost effectiveness analysis of HPV vaccination offered through genito-urinary medicine (GUM) and HIV clinics. This is on the basis that MSM who attend GUM clinics are a group at high risk of HPV infection and associated disease who receive very little health benefit from the highly successful HPV vaccination programme in adolescent girls. Following its October 2014 meeting, JCVI has published provisional advice that a targeted programme of HPV vaccination for MSM who attend GUM and HIV clinics

<sup>32</sup> <https://www.gov.uk/government/publications/living-well-for-longer-a-call-to-action-to-reduce-avoidable-premature-mortality>

<sup>33</sup> <https://www.gov.uk/government/publications/helping-people-live-well-for-longer>

should be introduced. JCVI agreed that further consultation was needed with stakeholders before finalising its advice to Ministers. This consultation is underway and will last for eight weeks from 12 November. JCVI's final advice is expected in March. The JCVI advice on vaccinating adolescent boys with HPV vaccine is not expected until February 2017.

- 3.5. From September 2014, the HPV vaccination programme reduced from a three dose to a two dose schedule following revised advice from the JCVI. Research shows that the antibody response to two doses in adolescent girls is as good as a three dose course in the age group where efficacy against persistent infection and pre-cancerous lesions has been demonstrated.

## Skin cancer

### Sunbeds

- 3.6. Sunbeds used for cosmetic tanning are known to be a cause of skin cancer. The World Health Organisation's International Agency for Research on Cancer classifies ultraviolet radiation and ultraviolet-emitting tanning devices as Class 1, "carcinogenic to humans" and, in its 13<sup>th</sup> report on health risks from artificial tanning devices in 2009, the Committee on Medical Aspects of Radiation in the Environment recommended that the commercial use of sunbeds needed regulation. This recommendation led to the adoption of a private members bill with cross party support, leading to the 2010 Sunbed Regulation Act. The Department of Health is commissioning work to review the regulation of commercially-operated tanning facilities. A recent report by the All Party Parliamentary Group on Skin<sup>34</sup> has also made a number of new recommendations to the Department of Health and we will take this and other evidence into account.

### Sun protection trends

- 3.7. Between 2003 and 2013, the Department of Health funded Cancer Research UK to collect data via ONS monthly omnibus survey to measure awareness, attitudes and reported behaviour of adults in relation to ultraviolet (UV) radiation and sun protection.
- 3.8. Some positive trends were observed in awareness of actions to reduce the risk of skin cancer, including 'avoid sunburn' (2003 to 2013) and 'avoid sunbeds' (2006 to 2013) which is encouraging. However, numbers who reported these actions were consistently low over the years (less than 25%).
- 3.9. The significant positive trends observed in awareness of actions to reduce the risk of skin cancer include 'protect children': 5.2% to 7.1%; 'avoid sunburn': 5.5% to 16.0%; 'check moles/skin for changes': 3.3% to 12.8%; and 'avoid sunbeds' (2006 to 2013): 11.6% to 21.6%.
- 3.10. Significant negative trends in awareness were observed for two of Cancer Research UK's three key messages: 'spend time in the shade' and 'cover up'. A decline was also observed for 'reduce time in the sun' (2007 to 2013), but this was not observed for men.
- 3.11. Results for reported sun protection behaviours also contrast with levels of awareness for many actions. For example, a significant increase in reported behaviour of 'cover up' was observed between 2003 and 2013 (+10.7 percentage points) and 'spend time in the shade', although this was between 2011 and 2013 only. The results are generally positive with significant positive trends observed for ten out of 14 behaviours, albeit six

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<sup>34</sup> <http://www.appgs.co.uk/publications/>

out of ten of those increases did have consistently low response rates (less than 20%). Only one significantly negative trend was observed, for 'wear a t-shirt'; however the decrease between 2008 and 2013 was relatively small and not of great concern since significant increases were observed in similar behaviours e.g. 'cover up'.

- 3.12. Further information is available from CRUK's report: *Trends in awareness and behaviour relating to UV and sun protection: 2003 to 2013*.<sup>35</sup>

## Smoking

- 3.13. The number of smokers in England is now at the lowest ever level. The 2013 figure of 18.4% is just below the national ambition to reduce rates of smoking by adults in England to 18.5% by the end of 2015, meeting this ambition two years early.<sup>36</sup> Whilst this is encouraging, around 8 million people in England still smoke, smoking remains a significant cause of health inequalities and there is much variation in smoking rates across the country.
- 3.14. The Department of Health continues to take action on tobacco control and to protect young people in particular from tobacco and nicotine addiction. New provisions introduced in the Children and Families Act 2014 allow for regulations to end smoking in private vehicles carrying children, introduce an age of sale for electronic cigarettes and change the law to stop adults buying tobacco or electronic cigarettes on behalf of children.
- 3.15. The Department of Health is 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. From April 2015 small shops and all businesses selling tobacco to the public will need to cover displays of tobacco.
- 3.16. Smoking is the greatest preventable cause of death in the UK and Sir Cyril Chantler's independent review found evidence of the public health gains to be achieved from standardised packaging. The Government held a consultation on proposals to introduce the regulations and are considering all aspects of the policy before making a final decision.
- 3.17. The Department of Health is working to implement new EU rules set out in the Tobacco Products Directive 2014/40/EC. These rules are particularly aimed at further reducing the initiation rates in children and include mandating a minimum of 20 cigarettes per pack or 30g for roll-your-own, increasing the size and prominence of text and picture warnings and banning flavours such as menthol.
- 3.18. PHE has continued its programme of high profile stop smoking campaigns, including the hard-hitting New Year's health harms *Toxic Cycle* campaign and *Stoptober*. PHE also collaborated with the British Heart Foundation to support No Smoking Day 2014.
- 3.19. PHE continues to help those who want to quit. Since January this year, PHE have had more than 500,000 orders of support products including the *Quit Kit*, Smokefree app, text support and email programme.

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<sup>35</sup> <http://www.cancerresearchuk.org/health-professional/prevention-and-awareness/sunsmart/about-the-sunsmart-campaign>

<sup>36</sup> Integrated Household Survey, January to December 2013: Experimental Statistics. 2014.

- 3.20. PHE promotes the implementation of NICE guidance to support those who want to stop smoking. Local stop smoking services remain the most effective method of support, providing a combination of behavioural support and medication which can increase likelihood of success by up to four times.<sup>37</sup>
- 3.21. For people who are not yet ready, willing or able to stop, PHE provides advice on reducing the harm of smoking, and promotes NICE and Medicines and Healthcare Products Regulatory Agency (MHRA) guidance on harm reduction activities, along with information on nicotine and how it can be used to reduce the harm of smoking.

## Alcohol

### Minimum Unit Pricing

- 3.22. Minimum Unit Pricing remains a policy under consideration, while additional evidence becomes available, but will not be taken forward at present in England and Wales.
- 3.23. The Government acknowledges the need to give careful consideration to any possible unintended consequences of Minimum Unit Pricing, such as its potential impact on the cost of living, the economic impact of the policy and increases in illicit alcohol sales. The UK is confident of the legal basis of the minimum unit pricing policy and support the Scottish Government in this area in both the UK courts and in Europe.

### Chief Medical Officer's review of the drinking guidelines

- 3.24. The Chief Medical Officer's guidelines review is now underway. The Guidelines Development Group has been established and is now considering the most appropriate methodology for developing lower risk alcohol guidelines. New draft guidelines are expected to be consulted on by summer 2015.

### Public Health Responsibility Deal – Alcohol Network

- 3.25. Around 130 alcohol retailers and producers have made voluntary commitments to help reverse rising trends in health harm. The best are demonstrating leadership and providing innovative solutions.
- 3.26. We are starting to see results that go beyond what was intended in early 2011, such as people drinking drinks with a lower alcohol content. We expect to see one billion less units of alcohol in people's drinks by the end of 2015 and have already seen a quarter of that achieved in the first year alone. Much alcohol-attributable harm occurs in middle or older age groups as a result of years of drinking above the lower risk guidelines. Even a relatively small reduction is likely to have a significant impact upon long-term and chronic illnesses in the population.
- 3.27. Independent research undertaken by Campden BRI, a consultancy, published in November shows that just under 80% of bottles and cans of alcohol now have the correct unit and health information on their labels – clear unit content, the Chief Medical Officer's lower-risk drinking guidelines and a warning about drinking when pregnant. This fulfils an industry-wide Responsibility Deal pledge on labelling.
- 3.28. The Government's response to the alcohol strategy consultation set a challenge to industry to deliver rapid action, through the Responsibility Deal, in the following areas:

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<sup>37</sup> [Performance of English stop smoking services in first 10 years: analysis of service monitoring data](#), West et al BMJ 2013;347:f4921

- 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.

### Treatment and targeted interventions

- 3.29. Local areas are best placed to tackle alcohol-related issues in ways that suit local needs. 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 three million adults every year.
- 3.30. PHE has published a report outlining the evidence base, return on investment and current models and availability of alcohol services for patients in secondary care. The next phase of this work is now underway. Pro-forma service specifications will be developed for the different service models based on expert consensus, and a minimum dataset by which services can demonstrate their impact will be identified.
- 3.31. PHE has been working with an expert group in order to publish guidance in December for local authority and NHS commissioners and providers on pathways for young people who present to Accident and Emergency with alcohol-related conditions.
- 3.32. Recently, eight pilot areas implemented actions to establish Payment by Results for drug and alcohol dependency. These pilots have concluded, but evaluation is underway to obtain the lessons learned from the pilots which will be disseminated to help the wider treatment community.

### Obesity

- 3.33. The Government is committed to tackling overweight and obesity which is a major risk factor for certain cancers. In October 2011, the Government published *Healthy Lives, Healthy People: A call to action on obesity in England*<sup>38</sup>, which sets out national ambitions for a downward trend in overweight and obesity in children and adults by 2020.
- 3.34. Public Health England published *Everybody Active, Every Day*<sup>39</sup>, an evidenced-based approach to physical activity. The evidence is clear that being active can reduce Type 2 diabetes, could prevent one in ten cases of stroke and heart disease. Being active every day can reduce the risk of development breast cancer by up to 20% and improve the lives of those living with cancer.<sup>40</sup>
- 3.35. Local authorities are responsible for tackling public health issues and have been given a ring-fenced budget of £8.2 billion over three years to help them tackle issues like obesity. They are supported by national bodies, including PHE, to help with evidence and advice, and create social marketing campaigns to support behaviour change.

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<sup>38</sup> <https://www.gov.uk/government/publications/healthy-lives-healthy-people-a-call-to-action-on-obesity-in-england>

<sup>39</sup> <https://www.gov.uk/government/publications/everybody-active-every-day-a-framework-to-embed-physical-activity-into-daily-life>

<sup>40</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/374914/Framework\\_13.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/374914/Framework_13.pdf)

- 3.36. More than 400,000 families registered with the January 2014 Change4Life ‘Smart swaps’ campaign, which encouraged people to cut fat, sugar and calories from their diet. Purchasing data from a representative panel of shoppers showed an 8.6% reduction of sugary carbonated beverage purchases during the campaign period of January compared to the same period in the previous year.
- 3.37. The Change4Life summer 2014 campaign focused on encouraging children to be more active. The ‘Ten minute shake-up’ involved a major new strategic partnership with Disney to make activity fun and accessible. More than 270,000 families signed up for the Shake-up Pack and there were over 600,000 visits to the online *Shake-Up Zone*.
- 3.38. In January 2015, Change4Life aims to help families to cut back on sugar consumption and to eat well with a major campaign including TV, radio, press and digital advertising and supported by an extensive partnership programme.
- 3.39. Under a voluntary agreement, businesses have agreed to sign up to pledges such as: the reduction of salt, calories, including sugar, and saturated fat; the removal of trans fats; increasing the consumption of fruit and vegetables; and labelling calories in out-of-home settings in order to inform customer choice.<sup>41</sup> In June 2013, the Government published details of the new UK-wide voluntary front of pack labelling system to help consumers make healthier food choices.
- 3.40. The Government made a commitment to “Inspire a Generation” by ensuring that all children and young people have opportunities to be physically active, enjoy sport and get into habits for a lifetime – as set out by the Government’s promotion of *Moving More, Living More*<sup>42</sup>. £180 million (of the total £450 million government investment) has been committed over three years into the School Sport Premium, over £30 million in the School Games programme, and £11.4 million in the Change4Life Sports Clubs programme; a total of almost £222 million.
- 3.41. The School Food Plan, published by the Department for Education in 2013, is designed to increase the quality and take up of school meals, and inspire a love of good food in children to help boost academic performance and allow them to lead healthy lives. The plan outlines actions to improve food and food awareness in schools. These include revising the existing school food standards, setting up breakfast clubs in schools with a high proportion of pupils entitled to free school meals, and including a separate strand for cookery in the new Design and Technology curriculum. Alongside this, from September 2014 every pupil in reception, year 1 and year 2 attending a state-funded school is now entitled to a nutritious and healthy free school lunch.
- 3.42. The NHS Health Check programme is a risk assessment and management programme aiming to help prevent heart disease, stroke, diabetes and kidney disease for people in England aged 40-74, with around 15 million people eligible. As well as identifying people at risk of these issues, the Health Check programme signposts people to lifestyle interventions such as services to help them lose weight. The benefits of the programme are likely to be extensive as the same factors increase the risk of developing several cancers, lung disease, and certain types of dementia. Last year over 2.8 million NHS Health Check offers were made and over 1.38 million appointments were taken up.

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<sup>41</sup> <https://responsibilitydeal.dh.gov.uk>

<sup>42</sup> <https://www.gov.uk/government/publications/moving-more-living-more-olympic-and-paralympic-games-legacy>

## Occupational cancer

- 3.43. The Health and Safety Executive (HSE) continues to take forward a number of actions to tackle the complex issues involved in preventing occupational cancer. The approaches used include interventions with stakeholders, targeted inspection initiatives and awareness raising activities, all with the aim of reducing the incidence of occupational cancer that currently stands at approximately 9,000 deaths and 14,000 new registrations each year.
- 3.44. One approach involves establishing active partnership groups with stakeholders in key industries through which co-ordinated and focused industry-wide initiatives to tackle occupational disease are developed. For example, the quarrying industry partnership team has worked together to develop an animated film used for training. The film highlights the health risks to quarry workers who may be exposed to respirable crystalline silica and other workplace dusts and shows workers the simple steps they can take to protect themselves. The film has been well received by the industry.
- 3.45. HSE has also launched a new 'Beware Asbestos' campaign that builds on the previously successful 'Hidden Killer' campaign aimed at tradespeople. This new campaign employs a new approach through the distribution of asbestos information kits at the point of sale using a commercial partner as well as distributing messages through suppliers and retailers. It seeks to raise awareness of the risks from asbestos and encourage behaviour change among those workers who may disturb asbestos-containing materials.
- 3.46. HSE is promoting further activity on preventing occupational cancer as well as capturing the activity undertaken by other organisations through a web-based community.<sup>43</sup>

## Aspirin

- 3.47. An international consensus statement on the prophylactic use of aspirin in the general population was published in August 2014.<sup>44</sup> This review of the published evidence showed that aspirin has real potential in reducing cancer incidence and mortality in the general population, with the strongest evidence for bowel, stomach and oesophageal cancers.
- 3.48. However there are still a number of remaining research questions, such as at what age should people start taking aspirin, for how long and at what dose? Research to answer some of these questions is ongoing. For example, a study looking at aspirin to prevent recurrence after treatment for early stage cancer (the ADD-ASPIRIN trial) is hoping to start recruiting nearly 10,000 patients by the end of 2014. The trial is jointly funded by the National Institute for Health Research and Cancer Research UK, will take place in the UK and India and will include patients who have had breast, bowel, oesophago-gastric and prostate cancers.
- 3.49. The National Institute for Health and Care Excellence (NICE) published a Medicine Evidence Commentary, *Aspirin: primary prevention of cancer and cardiovascular disease*, in November 2014. The commentary summarised the review, and concluded that the decision by an individual about whether or not to take prophylactic aspirin is likely to be dependent on their view of the risks and benefits, their own values and preferences, and their individual social and clinical circumstances. After running a

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<sup>43</sup> <http://webcommunities.hse.gov.uk/connect.ti/OccupationalDisease/grouphome>

<sup>44</sup> <http://annonc.oxfordjournals.org/content/early/2014/07/30/annonc.mdu225.abstract>

workshop with GPs at their request, Cancer Research UK has agreed to produce a public-facing leaflet on aspirin, which GPs will be able to give out. Cancer Research UK hope to have this completed by mid-2015.

## Extending and expanding the cancer screening programmes

3.50. NHS England directly commissions routine cancer screening programmes through the Public Health Section 7a agreement with the Department of Health, 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. They cover the scope of the cancer screening programmes and quality assurance requirements. High level assurance of programme outcomes is conducted jointly by NHS England, the Department of Health and PHE.

### Breast cancer screening

3.51. As at October 2013, 61 out of 80 local programmes (76%) had entered the breast screening age extension randomisation trial to women aged 47 to 49 and 71 to 73, and a further nine (11%) which are unsuitable for randomisation were inviting only the 47 to 49 year olds. Nearly two 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.

3.52. Ten local programmes (12.5%) are still to expand, citing lack of digital mammography equipment and shortage of staff as issues. As at October 2013, 78 (98%) of local programmes had at least one direct digital mammography x-ray set and 69 (86%) were fully digital. Worthing has been offering digital mammography since December 2013, and North Cumbria will be implementing digital mammography in early 2015.

### Cervical screening

#### HPV testing as triage and test of cure

3.53. HPV testing as triage (sorting) for women with low-grade dyskaryosis or borderline cervical screening test results and HPV testing as 'test of cure' for women receiving treatment as a result of screening became routine as part of the NHS cervical screening programme in April 2014. The impact assessment of IOSC stated that introducing HPV testing in this way would be more targeted and would significantly reduce the need for repeat testing, and is therefore expected to yield significant net savings of up to £16 million a year. Over 160,000 women a year will not need repeat tests due to mild or borderline results and around 400,000 women will be removed from ten year annual follow-up due to a previous abnormal result.

#### HPV primary screening

3.54. The UK National Screening Committee (UK NSC) has given its support for a pilot to assess the value of using HPV testing as the primary screening test for cervical disease, rather than the currently used cytology test. The pilot programme began in May 2013 and is 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 has been successful, HPV primary screening will be rolled out across England, subject to a recommendation by the UK NSC and the Public Health Section 7a agreement. Cancer Research UK has estimated that, when fully implemented, HPV primary screening could prevent an additional 600 cases of cervical cancer a year.

## Bowel cancer screening

- 3.55. As at the end of September 2014, more than 23 million invitations had been sent out since the NHS bowel cancer screening programme began in 2006 and nearly 13 million people had adequately participated.
- 3.56. Over 20,000 cancers had been detected, and over 113,000 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 just over 280,000 have self-referred for screening so far.
- 3.57. The age extension of the programme to men and women aged 70 to their 75th birthday is nearing completion. As at December 2014, 57 of the 58 local screening centres (98%) had implemented the extension. The last centre to implement age extension is Harrogate, Leeds and York. The extended age range became routine from April 2014.

## Faecal Immunochemical Testing (FIT)

- 3.58. The original strategy set out how NHS cancer screening programmes will be looking at how the more accurate and simpler to use FIT may be introduced into the programme in an effort to increase uptake and to provide more accurate results.
- 3.59. NHS Cancer Screening Programmes began piloting FIT in April 2014. The pilot will involve 40,000 people spread over the screening centres attached to two of the regional programme hubs. Findings from the pilot will be available in the spring of 2015.

## Bowel Scope Screening (BSS)

- 3.60. Screening for bowel cancer using a single flexible sigmoidoscopy (Bowel Scope Screening, BSS) between 55 and 64 years of age, removing small polyps by BSS and providing full colonoscopy for "high risk" polyps was investigated during a randomised controlled trial funded by Cancer Research UK, the Medical Research Council and NHS Research and Development took place in 14 UK and six Italian centres.
- 3.61. The study concluded that BSS is a safe and practical test and, when offered only once between ages 55 and 64 years, confers a substantial and long lasting benefit. The UK NSC reviewed the evidence, and in April 2011 concluded that screening for bowel cancer using BSS meets the UK NSC criteria for a screening test. In England its implementation is managed by NHS Cancer Screening Programmes.
- 3.62. Research has shown that a one-off bowel screening procedure using flexible sigmoidoscopy (bowel scope screening) can prevent bowel cancer developing by finding and removing polyps in people in their mid to late 50s. Bowel scope screening was piloted from April 2013 at six sites: Norwich; South of Tyne; St Mark's, London; Surrey; West Kent and Wolverhampton.
- 3.63. As at 31 March 2014, 22 screening centres were offering BSS to their eligible population. This represents 36.6% of the total number of screening centres in England, exceeding the Government's target of 30%.
- 3.64. PHE are confident that, in addition to the 23 screening centres that are currently live, the required number of screening centres needed to meet the 60% target by 31 March 2015 will be achieved. Implementation of the service to all screening centres will be accomplished by the end of 2016.
- 3.65. As at September 2014, over 54,000 invitations had been issued and over 18,000 procedures performed. Uptake stood at 45.7%, and ranged from 38% in the lowest site to 50% in the highest. 3.2% of people were being referred to colonoscopy following bowel scope screening, and over 576 people had polyps retrieved.

## Raising awareness and removing barriers to bowel screening participation

- 3.66. Despite the successes of the bowel cancer screening programme (BCSP), coverage remains low compared to other cancer screening programmes. Between January and April 2014, Cancer Research UK, with support from PHE, NHS England (London region), the Department of Health and the BCSP tested a number of different approaches to raising awareness of the programme and reducing barriers to participation in London. The approaches tested included various different combinations of an endorsement of the programme from Cancer Research UK, a 'kit enhancement' designed to make it easier for people to complete the test, and outdoor advertising to raise awareness of the programme. People in the target age range for the bowel cancer screening programme received none, one or both of the kit enhancement and endorsement letter. Outdoor advertising was only displayed in north-east London, to test the additional effect of advertising on top of other interventions.
- 3.67. The evaluation of the programme showed that although the endorsement letter did not significantly impact uptake of screening on its own, the endorsement letter and kit enhancement together increased uptake by 0.9% to 2.7%. Similar results were seen for the outdoor advertising campaign and the endorsement letter combined. The outdoor advertising campaign, endorsement letter and kit enhancement, when all were taken together, increased uptake by 2.1% to 6.0% among 60 to 69 year olds, and 2.6% to 4.6% among 70 to 74 year olds.
- 3.68. These results are promising, and Cancer Research UK plan some further testing in partnership with the Welsh bowel cancer screening programme in early 2015.

## Screening for other cancers

### Prostate cancer screening

- 3.69. The latest data from the European Randomised Study of Screening for Prostate Cancer (ERSPC) with 13 years follow-up was published in *The Lancet* in August 2014. These data showed that death rates from prostate cancer were 21% lower among participants who were given Prostate Specific Antigen (PSA) screening compared to those who had not. Men who were actually screened had a 27% lower chance of dying from prostate cancer. However, to prevent one death from prostate cancer at 13 years of follow-up, 781 men would have to be invited for screening and 27 cancers would need to be treated.
- 3.70. The UK NSC does not recommend screening men for prostate cancer because the risks of over-diagnosis far outweigh 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 and risk-benefit profile and lead to a feasible, effective screening programme. The UK NSC will continue to review their position on prostate cancer screening at regular intervals and as new research data become available.
- 3.71. PSA testing can, of course, be performed on request in asymptomatic men over 50 years of age. Information is provided by the Prostate Cancer Risk Management Programme (PCRMP) on the risks and benefits of PSA testing to help primary care practitioners to counsel men who enquire about prostate cancer and the PSA test. PHE is due to review the pack that supports the PCRMP in 2015.

### Lung cancer screening

- 3.72. 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 the UK NSC will 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

- 3.73. The UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) began in 2000, and 200,000 post-menopausal women aged 50 to 74 were randomised in 12 UK centres. Half the women have been screened, either by annual CA125 blood test or annual trans-vaginal ultrasound, with the remainder as the control group. The trial 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 trial is expected to cost some £20 million, with final results known in 2015.

### Be Clear on Cancer

- 3.74. PHE, in partnership with the Department of Health and NHS England (including NHS Improving Quality), have run a number of *Be Clear on Cancer* (BCOC) campaigns this year. The aim of these campaigns is to highlight the signs and symptoms of a range of cancers and to encourage people with the relevant signs and symptoms to visit their GP.
- 3.75. The National Cancer Intelligence Network (NCIN), as part of PHE, have been leading on the evaluation of the campaigns from April 2013, whilst Cancer Research UK have continued to provide elements of programme management, social marketing support and evaluation of campaigns prior to April 2013.
- 3.76. The 2014 campaigns have focused on:
- a national campaign on breast cancer in women over 70 from February to March 2014, following the success of the regional pilot in early 2013;
  - regional campaigns on oesophago-gastric (in the North East and Border TV regions) and ovarian (in the North West TV region) cancers from February to March 2014;
  - a repeat of the national lung cancer campaign from March to the end of April 2014;
  - a local skin cancer pilot in the South West, from June to July 2014 (results awaited);
  - a repeat of the national campaign on bladder and kidney cancers from October to November 2014 (results awaited);
  - a local pilot on prostate cancer in black men, running in six London boroughs from October to November 2014 (results awaited).
- 3.77. Following the success of the regional oesophago-gastric campaign, it was announced in September 2014 that this campaign will run at a national level from 26 January to 22 February 2015. The key campaign message will be: 'Having heartburn, most days for 3 weeks or more, could be a sign of cancer - tell your doctor'. A second message will focus on: 'Food sticking when you swallow could be a sign of cancer – tell your doctor'.
- 3.78. Using the successful award winning approach that BCOC has developed, two campaigns focusing on non-cancer conditions will also run in early 2015.

- 3.79. Decisions on further BCOC activity will be made during 2015.
- 3.80. Resources for all the campaigns can be found on the National Awareness and Early Diagnosis Initiative (NAEDI) website. 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 and CRUK providing the secretariat.
- 3.81. A comprehensive summary of the evaluation results up until February 2014 is available on the NAEDI website.<sup>45</sup>

### Evaluation of cancer awareness campaigns

- 3.82. Evaluation of the cancer awareness campaigns is a comprehensive ongoing programme, comprising measurements from key stages of the patient pathway. A variety of different information is used, including (but not limited to) assessments of cancer awareness levels, attendances at GP practices, levels of urgent referrals and numbers of cancers diagnosed. Some of the information required takes longer to collate and analyse but gradually over time, when combined together, the metrics build up a detailed picture of potential campaign effects. Detailed evaluation results are in Annex C, and a summary for each campaign is below.

#### National lung cancer (first and second reminder campaigns)

- 3.83. The first national lung cancer campaign ran in late spring 2012, with reminder campaigns in summer 2013 and again in spring 2014. Initial results of the reminder campaigns demonstrate an overall upward trend in the number of urgent GP referrals, greater in women than in men. To date, the results suggest that both reminder campaigns may have resulted in small additional increases in referrals for suspected lung cancer and may have reinforced the key messaging from the first national campaign.
- 3.84. The first reminder campaign does not appear to have had an impact on: the number of lung cancers diagnosed following an urgent GP referral; the conversion rate; the number of lung cancers recorded in the cancer waiting times database or the detection rate.

#### National bowel cancer campaign

- 3.85. Further evaluation of the 2012 national bowel cancer campaign shows evidence of a statistically significant increase in the number of bowel cancers diagnosed following the launch of the campaign. Although there was no evidence of an increase in the number of bowel cancers diagnosed at an early stage following the campaign, there appears to have been a statistically significant decrease in the proportion of bowel cancers diagnosed following an emergency presentation during the months after the campaign finished.

#### National 'blood in pee' campaign

- 3.86. The first national blood in pee campaign, which ran in autumn 2013, demonstrated increasing awareness of blood in pee as a symptom of kidney or bladder cancer, with more people spontaneously mentioning blood in pee as a symptom. Confidence in the knowledge of signs and symptoms of kidney or bladder cancer also increased significantly from pre to post campaign, with men more likely than women to find the advertising relevant and feeling it told them something new.

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<sup>45</sup> <https://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/be-clear-on-cancer/about-be-clear-on-cancer>

- 3.87. There is evidence of an increase in the number of urgent GP referrals for suspected urological cancers during the campaign period, and some evidence that this campaign may have had a sustained impact. However, there was no significant change in the kidney cancer conversion rate for England. Initial estimates suggest that the number of kidney cancers recorded increased, as did the number of urological cancers, although there was no significant change for the number of bladder cancers.

### **National breast cancer in women over 70 campaign**

- 3.88. A campaign to increase awareness of breast cancer in women over the age of 70 ran in February and March 2014. Pre- and post-campaign awareness surveys were conducted with women. Among those aware of general cancer advertising, the proportion of women spontaneously mentioning breast cancer rose significantly pre to post campaign. Confidence in knowledge of signs and symptoms of breast cancer also increased significantly following the campaign. The campaign itself was well recognised, with many agreeing that the advertising would prompt them to talk to somebody close to them about the symptoms to watch out for.
- 3.89. As well as increasing awareness, the campaign appears to have resulted in a large increase in urgent GP referrals in the target age group. Some initial interim analysis also suggests a significant increase in the number of women aged over 70 self-referring for breast screening.
- 3.90. Initial estimates also suggest that the number of breast cancer diagnoses increased significantly for women aged 70 and over, with further analysis demonstrating significant increases in the number of diagnoses resulting from urgent GP referrals.

### **Regional oesophago-gastric campaign**

- 3.91. Following evaluation of a local pilot, the regional oesophago-gastric campaign ran in the Tyne-Tees and Border TV regions in February and March 2014. High levels of people reported seeing any advertising/publicity about cancer and publicity about cancer symptoms. The campaign recognition was the highest to date for a regional pilot, especially of the TV advertisement, with high levels of people saying it told them something new.
- 3.92. The campaign appears to have resulted in a large increase in referrals for suspected upper gastrointestinal (GI) cancers, larger for men than women. Although there is no initial evidence that the campaign had an impact on the total number of relevant cancers diagnosed, there is some evidence that the campaign may have had an impact on detection rates for oesophageal, stomach and upper GI cancers.

### **Regional ovarian campaign**

- 3.93. The regional ovarian cancer campaign ran in the Granada TV region in February and March 2014. Very high levels of women in the pilot region reported seeing any advertising/publicity about cancer. Of these when asked to describe the publicity, good levels in the pilot region spontaneously mentioned 'bloating' at the post stage. There was an overall significant increase in confidence in the knowledge of ovarian cancer symptoms pre to post campaign, with encouraging increases in prompted knowledge of a range of ovarian cancer symptoms. The campaign material was well recognised, especially the TV advertisement. High levels of women also said that the advertising told them something new, whilst some women who recognised the advertising made appointments with their GP.
- 3.94. Other initial results we have for the campaign are less clear. Although we have evidence of an increase in the number of gynaecological urgent GP referrals, we have not

identified any evidence of impact on the number of cancer diagnosed or on the detection rate.

### Reducing inequalities in raising awareness of cancer symptoms

- 3.95. *Be Clear on Cancer* campaigns have very clear target audiences primarily aimed at those over 50 (with the exception of the breast cancer campaign which was aimed at women over 70) and positive results have been seen in older populations for lung, blood in pee and the oesophago-gastric campaigns.
- 3.96. The clearest peak in increased urgent referrals for suspected lung cancer for April 2014 (during the second lung reminder campaign) was seen for those aged in their 60s and 70s.
- 3.97. For the first national 'blood in pee' campaign, of the cancer diagnoses resulting from an urgent referral for suspected cancer, the number of bladder, kidney and urological cancer diagnoses increased for those aged 50 to 59 (urological cancers only), 60 to 69 and 70 to 79. Those aged 70 to 79 had the largest increases, ranging from 19% (bladder) to 56% (kidney).
- 3.98. Of the diagnosed cancer cases recorded on the cancer waiting times database, the number of bladder cancers decreased by 11% for those aged 80 and above, and by 11% for females. The number of kidney cancers increased by 24% for those aged 70 to 79 and by 13% for males. The number of urological cancers increased by 14% and 15% for those aged 60 to 69 and 70 to 79, respectively, and by 11% for males.
- 3.99. For the regional oesophago-gastric campaign, larger increases in suspected upper GI cancer referrals were found for those aged in their 50s (85%) and 60s (69%), with a smaller increase for those aged 80 and over (18%).
- 3.100. The results for the ovarian campaign however show that all age groups in the regional pilot area had statistically significant increases in the number of referrals for suspected gynaecological cancers. The largest increase was for the under 50 age group (35%) and the smallest increase for the 70 to 79 age group (14%).
- 3.101. There is some evidence to suggest that the campaigns are successfully targeting harder to reach groups (for instance, more deprived people and men). For the first national bowel campaign:
- significantly more men than women said the campaign adverts told them something new (55% vs 48%), felt the adverts were relevant to them (70% vs 64%), and reported booking a GP visit after seeing/hearing the adverts (7% vs 4%)
  - there was also a larger increase in men visiting their GP with key campaign symptoms during the period compared with the previous year than for women (37% for men vs 22% for women).

### Prostate cancer in black men pilot

- 3.102. In partnership with Prostate Cancer UK, PHE ran a local *Be Clear on Cancer* pilot in London to raise awareness of the increased risk of prostate cancer amongst black men aged 45+. The pilot ran between 20 October and 23 November 2014 in six London Boroughs: Hackney, Haringey, and Newham in north-east London, and Lambeth, Lewisham and Southwark in south-east London. The key message of the campaign was: '1 in 4 black men will get prostate cancer. Prostate cancer often has no obvious

symptoms. If you are a black man over 45 and want to discuss your personal risk of prostate cancer, visit your GP.’ Evaluation results of the pilot are awaited.

## Supporting general practitioners to diagnose cancer earlier

### NICE referral guidelines for suspected cancer

- 3.103. On 20 November 2014, NICE began a consultation on a draft of *Suspected cancer: recognition and management of suspected cancer in children, young people and adults*, a revision of NICE’s original referral guidelines from 2005.<sup>46</sup> NICE is updating the guideline to make it as simple as possible for GPs to consider the possibility of cancer and refer people to the right service at the right time. The consultation proposes a uniform risk threshold of referral for diagnostic tests, when there is a risk of cancer of around 3%. This is lower than before for some cancers.
- 3.104. The draft guideline uses tables to clearly set out which symptoms could be linked to which cancers and provides clear recommendations for tests and referral to specialist services, and how long people should wait to be seen by a specialist once they have been referred to hospital. It also includes a series of new and updated recommendations about ‘safety netting’ and how best to reassure, support and inform patients with suspected cancer and their families. The consultation runs until 9 January 2015.

### ACE

- 3.105. In partnership with Cancer Research UK and Macmillan Cancer Support, NHS England is developing a national programme of work on early diagnosis of cancer that would help Accelerate, Coordinate and Evaluate (ACE) learning from innovative projects led locally by the NHS. These projects will explore best practice and innovative ideas, producing a national body of evidence and evaluation that is robust and can be used by commissioners. Key questions include: how to streamline pathways to deliver faster diagnosis and how to improve the uptake of screening. Some of the ideas and concepts being tested include: straight to diagnostic test; merging of referral routes; and, multi-disciplinary diagnostic centres, amongst others.

### Macmillan Cancer Support Clinical Decision Support Tool

- 3.106. In 2013, Macmillan Cancer Support, partly funded by the Department of Health, 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. A full evaluation of the pilot will be published by Cancer Research UK. The 2013 project was recognised as a Health Service Journal Value in Healthcare award winner.
- 3.107. In 2014 the original electronic cancer decision support tool has been refined, with more tumour sites added, and is currently installed in over 1,000 GP practices across the UK. Macmillan Cancer Support is working in partnership with companies supplying GP IT, to develop versions of this software and make it available to all GPs as part of their standard software offer. A web version of the software will be available in late 2014, with others to follow.

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<sup>46</sup> <http://www.nice.org.uk/guidance/gid-cgwave0618/resources/suspected-cancer-draft-guideline2>

## Cancer Research UK GP Engagement Partnership

### Primary Care Engagement Project

3.108. Building on the success of the two pilot areas, Cancer Research UK, with some additional investment from the NHS, expanded the facilitator project in 2014 to cover over 1,000 practices across 26 CCGs in London, Merseyside, Cheshire, Oxfordshire, Berkshire and Buckinghamshire. An external evaluation of the pilots<sup>47</sup> showed that facilitators are effective agents of change and have a positive impact at both practice and CCG level. By working with GP practices to implement quality improvement measures such as reviewing practice profiles, undertaking cancer audits or significant event audits and using risk assessment tools, facilitators are helping to reduce variation in practices in relation to urgent suspected cancer referral (two week wait referrals). Cancer Research UK will now significantly increase its investment to roll out the facilitators across the UK in a phased approach over the next few years.

### Cancer Network GP leads

3.109. Cancer Research UK is funding strategic GP leads in each of the English Strategic Clinical Networks. Working closely with primary care facilitators, these posts play a key role in helping to reduce primary care variation by coordinating activities of local CCG cancer leads and developing more effective links with the new Clinical Senates, Local Education and Training Boards, Academic Health Science Networks and NHS England Area Teams. Cancer Research UK will increase its investment to fund more of these posts over the next few years to give a particular focus on further developing local care pathways.

## Early and rapid access to diagnosis of the symptoms of breathlessness

3.110. NHS Improving Quality (NHS IQ), the health service improvement body, is recruiting pilot areas from across the country currently working on or planning to develop and test new service models and pathways for earlier and rapid diagnosis of breathlessness symptoms through improved access to diagnostics.

3.111. Breathlessness is a common symptom of a range of cancer and non-cancer diseases including lung cancer, heart failure, chronic obstructive pulmonary disease and others. This work will link with other early diagnosis of cancer programmes, such as *Be Clear on Cancer*, to build on their work and share learning. NHS IQ will be evaluating the outcomes of the work with the aim to provide evidence for commissioning and spread of new models from 2015/16 onwards.

3.112. Following a local pilot campaign earlier in 2014 on raising awareness of the symptom of breathlessness, the campaign will be run at a regional level in the east of England from 2 February 2015 for four weeks.

3.113. The campaign will be led by PHE in partnership with the Department of Health and NHS England and will introduce TV advertising. It will again aim to encourage those with inappropriate breathlessness (breathlessness that is disproportionate to the level of activity undertaken) to go and see their GP. The campaign primarily aims to diagnosis heart and lung disease earlier, with scope to reduce premature mortality and to improve the quality of life of those living with these conditions.

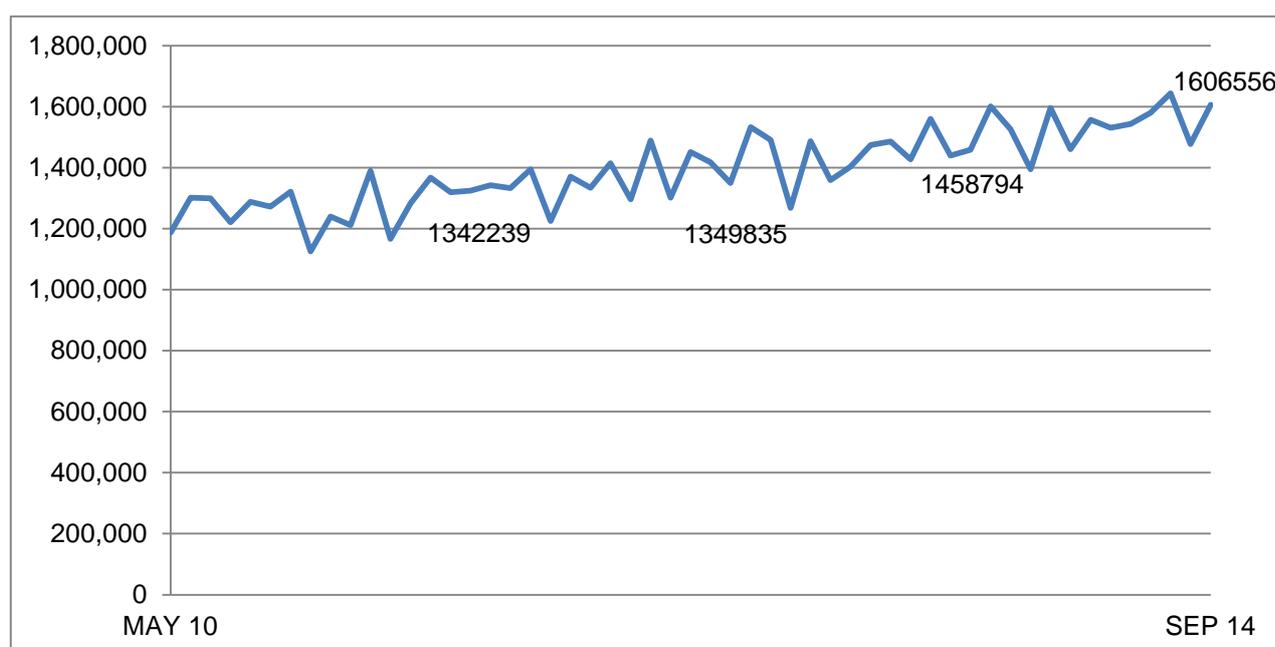
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<sup>47</sup> *Evaluation of the Cancer Research UK Primary Care Engagement Facilitator Initiative 2013/14*, Ablett-Spence, I, et al. Durham University 2014

## Diagnostic activity

- 3.114. The NHS carried out over 1.6 million tests in September 2014. Despite this increase, the percentage of people waiting six weeks or more for a test at the end of September 2014 was just 1.5%, a small proportion of the total patients waiting for a diagnostic test.
- 3.115. In 2013/14, the NHS in England performed on average over 300,000 more diagnostic tests each month compared to 2009/10, including:
- almost 15,000 more endoscopy tests that are used to detect bowel and stomach cancers
  - over 64,000 more MRI scans
  - over 97,000 more CT scans
  - over 103,000 more non-obstetric ultrasound tests.

**Figure 4 Number of diagnostic tests performed monthly from May 2010 to September 2014**



## Endoscopy services

### Work to increase endoscopy capacity

- 3.116. On behalf of the Joint Endoscopy Working Group set up by the NHS England National Clinical Director on Diagnostics and Imaging, the Joint Action Group (JAG) on gastrointestinal (GI) endoscopy undertook a capacity review of endoscopy units, which reported in October 2014 and is currently being analysed. In addition, the Government's mandate to Health Education England (HEE) stated that "HEE will work with PHE and NHS England to ensure the availability...of sufficient endoscopists to deliver bowel scope screening."

### NHS IQ Productive Endoscopy Programme

- 3.117. The *Productive Endoscopy Series* is a set of self-directed learning resources that will help all staff working in endoscopy units to make better use of existing resources and

deliver a more efficient and effective service to patients seven days a week. The series was launched in 2014. The series is a set of 'how to' guides to help staff make improvements in endoscopy services and meet the quality improvement elements of the Global Rating Scale, and accreditation of service. The series is endorsed by the JAG.

- 3.118. Based on the principles and methodology of *Productive Operating Theatre* the series will help units to reduce waste through better workplace organisation, offering support processes, guidance for scheduling processes and improvement of information and patient flow - leading to reductions in errors and delays.

## 4. Treatment

### Introduction

4.1. Alongside prevention and early diagnosis, it is vital that patients are able to access the most appropriate treatment quickly, delivered to the highest quality, with an expectation of a positive patient experience. Over the last year we have continued to push forward improvements in the treatment offered by the NHS, including action on surgery, radiotherapy and chemotherapy. This chapter outlines the key developments over the last year across all three major arms of cancer treatment, as well as waiting times for patients accessing those treatments.

### Cancer waiting times

- 4.2. 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 services, produced by NHS England, were released on 19 November 2014 according to the arrangements approved by the UK Statistics Authority.
- 4.3. National performance against the majority of cancer waiting times measures continues to remain broadly stable. However, the NHS is under pressure because of unprecedented demand and disappointingly the standard for patients receiving first treatment within 62 days of urgent GP referral for suspected cancer for all cancers was missed in quarter four of 2013/14 and quarters one and two of 2014/15. Quarter four 2013/14 was the first time this standard had been missed. We expect the NHS to look urgently at any dips in local performance and take action to make sure all patients get access to cancer treatment as quickly as possible.
- 4.4. Table 4.1 shows both the level of achievement for quarter one (April to June 2014) and quarter two (July to September), 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 2014**

Waiting time measure	Operational standard	Quarter one 2014/15 achievement	Quarter two 2014/15 achievement
Two week wait for all suspected cancers	93%	93.5%	93.6%
Two week wait for breast symptoms (where cancer was not initially suspected)	93%	90.3%	93.5%
<b>Waits for first treatment</b>			
First treatment within 31 days of	96%	97.8%	97.7%

Waiting time measure	Operational standard	Quarter one 2014/15 achievement	Quarter two 2014/15 achievement
diagnosis for all cancers			
First treatment within 62 days of referral for all cancers	85%	84.1%	83.5%
First treatment within 62 days of NHS cancer screening service referral	90%	93.8%	94.1%
<b>Waits for second/subsequent treatment</b>			
Within 31 days where the subsequent treatment was surgery	94%	96.2%	96.0%
Within 31 days where the subsequent treatment was an anti-cancer drug regime	98%	99.7%	99.6%
Within 31 days where the subsequent treatment was a course of radiotherapy	94%	97.1%	97.3%

## Surgery

### Enhanced Recovery care pathways seven days a week

- 4.5. Enhanced Recovery (ER) as a model of care delivery is continuing to spread across England with the support of NHS Improving Quality. 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 is an evidence based model of care delivery which provides efficient, effective elective care delivery for the NHS. ER has a variety of benefits, improving patient experience, patient safety and patient outcomes as well as the potential efficiency gains that can be realised locally.
- 4.6. The ER pathway is underpinned by 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.
- 4.7. ER's ability to reduce length of stay without increasing readmissions provides real efficiency benefits for the NHS. Good progress continues to be made in reducing the length of stay for elective surgical procedures and there is growing evidence of the spread of ER principles beyond elective procedures to non-elective surgical procedures.

- 4.8. Proactive management to help patients get better more quickly has resulted in a reduction in lengths of stay. Despite rises in activity for almost all of the eight elective procedures that first adopted ER nationally, there were nearly 200,000 fewer bed days for these procedures in 2013/14 than in 2008/09. 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.
- 4.9. 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;
  - develop internationally comparable outcome measures to build further on the evidence base.
- 4.10. 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.

## Radiotherapy

### Radiotherapy levers for change

- 4.11. In March 2014, *A Vision for Radiotherapy*<sup>48</sup> was published jointly by Cancer Research UK and NHS England and during 2014 a review of the future radiotherapy demand was undertaken in order to reassess the future capacity requirements in England to 2020. The findings of this review, available in late December, will enable commissioners to undertake a local needs assessment to include the impact of technological developments and efficiencies and changing clinical practice (including fractionation). The results will inform the next steps to be taken by NHS England to ensure that a single approach to addressing capacity issues is adopted. Both documents describe a direction for radiotherapy with emphasis on:
- patient access to a wider range of innovative treatments and quality;
  - the impact of technological and clinical practice developments;
  - sustaining services through partnerships; and
  - services based on wider catchment populations based on quality standards.
- 4.12. In line with NHS England and Cancer Research UK's *Vision for Radiotherapy*, the priority for the Clinical Reference Group is the wide scale adoption of innovative radiotherapy technology by driving forward on completely overhauling the radiotherapy

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<sup>48</sup> [http://www.cancerresearchuk.org/sites/default/files/policy\\_feb2014\\_radiotherapy\\_vision2014-2024\\_final.pdf](http://www.cancerresearchuk.org/sites/default/files/policy_feb2014_radiotherapy_vision2014-2024_final.pdf)

equipment stock over the next five to ten years. This also allows enhanced quality to be coupled with opportunities for greater throughput and efficiency.

- 4.13. The radiotherapy service specification for NHS England was introduced in October 2013. It will be important to update the service specification in line with the published *Vision for Radiotherapy* as well as referencing a number of clinical commissioning policy statements aimed at reducing variation in clinical practice across England. The National Radiotherapy Dataset (RTDS) will be used to monitor quality and move towards a focus on patient outcomes measures.
- 4.14. The Radiotherapy Innovation Fund of £23 million was distributed to 50 centres in 2012 in order to support the development of Intensity Modulated Radiotherapy (IMRT) techniques at departmental level to meet the Prime Minister's pledge that all patients eligible for innovative radiotherapy, where clinically appropriate and cost effective, should have access to it. The standard identified within the service specification was a minimum 24% inverse planned IMRT, an advanced form of radiotherapy.
- 4.15. Since April 2013, there has been an England wide increase in the delivery of IMRT activity, with the England average now at 35% with the majority sustaining the standard on a three month rolling average.
- 4.16. In 2014, two clinical commissioning policy statements were developed by the Radiotherapy Clinical Reference Group and implemented by NHS England to support a drive to reduce variation in clinical practice. The implementation of these schemes is closely monitored by NHS England.

### **Stereotactic Ablative Body Radiotherapy (SABR)**

- 4.17. SABR is an innovative form of radiotherapy treatment which uses an ablative (or destructive) dose of radiation to be delivered in fewer treatment fractions with the prospect of improving tumour control and reducing side effects to other tissues.
- 4.18. The treatment of early stage non-small cell lung cancer by SABR is supported by scientific evidence as a treatment option. As such, this treatment is routinely commissioned by NHS England for patients who meet the clinical criteria and are not suitable for surgery.
- 4.19. In response to concerns expressed regarding the limited access to SABR for patients with other cancers, and in the absence of clinical evidence, NHS England has agreed to make up to £6 million funding to support new Cancer Research UK clinical trials, available over the lifetime of the trials, to evaluate the clinical benefits of this intervention.
- 4.20. In this way more patients will be able to receive SABR treatment – but as part of a clinical trial, meaning that at the same time the effectiveness of these treatments will be assessed so that the clinical evidence can inform future NHS England commissioning policy.
- 4.21. Cancer Research UK is already recruiting to one of the trials for the treatment of prostate cancer, and has committed support to an additional four trials with a further trial being considered in the near future.
- 4.22. Opportunities to evaluate the benefits of its potential utility in patients with oligometastatic disease in tumour sites not included in the current trials portfolio are also being explored by NHS England.

### Proton Beam Therapy (PBT)

- 4.23. Patients suitable for PBT abroad currently travel for treatment at specialist centres in the USA (Jacksonville and Oklahoma) and Switzerland (Villigen). Of the 675 patients referred for consideration for treatment since the programme started in 2008, 524 have been approved for treatment, of which 379 (72%) are children.
- 4.24. Planning and development for PBT centres at the Christie in Manchester and University College London Hospitals continues. The procurement process for the equipment has been launched with the buildings to follow.
- 4.25. The commissioning policies for PBT are within NHS England's routine advice and governance processes for directly commissioned specialised services. These are under review in line with emerging research and best practice, to ensure appropriate clinical indications are identified and will support the transition from the overseas programme to the future programme starting in 2018. Discussions are underway to allow inclusion of patients from the devolved administrations.

### Selective Internal Radiotherapy (SIRT)

- 4.26. SIRT is available to patients in England through a Commissioning through Evaluation programme. NHS England is using this programme to help determine whether SIRT might be routinely commissioned by the NHS in the future. Specifically, there are two indications currently included in the Commissioning through Evaluation scheme for SIRT, Colorectal Liver Metastases and Intrahepatic Cholangiocarcinoma
- 4.27. Since the programme began in late 2013, 95 patients have been treated using SIRT.

### Chemotherapy

- 4.28. Chemotherapy services have been directly commissioned by NHS England since April 2013 and chemotherapy service specifications for NHS England were implemented on 1 October 2013. A key requirement of these specifications is that all providers of chemotherapy services have in place an electronic prescribing system. There has been progress since then in working with providers to support improvements in the use of e-prescribing for all types of chemotherapy.
- 4.29. 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:
- national chemotherapy algorithms have been drafted for a range of common malignancies (including myeloma, breast, lung, colorectal, prostate and renal) and it is anticipated that these will be agreed through NHS England for 2015/16
  - minimising variation in practice, partly by algorithms but also by data-driven presentation of outputs from the Systemic Anti-Cancer Therapy database
  - management of the Cancer Drugs Fund to deliver the greatest degree of clinical value to cancer patients. A consultation has recently been held on proposals to ensure a sustainable Cancer Drugs Fund up until March 2016
  - providing clinical advice to NHS England on QIPP schemes – including those around best practice in oral chemotherapy prescribing, implementation of sub-cutaneous Rituximab and palliative chemotherapy

- partnerships with the cancer charities and patient groups, the Association of British Pharmaceutical Industry, NICE and NHS England in delivering a strategy for the sustainable funding and commissioning of systemic therapy for cancer
- 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.

### Cancer Drugs Fund

- 4.30. The Government established the Cancer Drugs Fund from 1 April 2011 to help patients get the additional cancer drugs their doctors recommended. The Fund originally provided £200 million 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.
- 4.31. Since October 2010, this funding has helped over 60,000 cancer patients in England to access the additional cancer drugs their doctors think they need.
- 4.32. The Government announced in September 2013 that a further £400 million would be made available to extend the Fund to the end of March 2016. On 28 August 2014, it was announced that an additional £160 million would be made available in 2014/15 and 2015/16, increasing the amount available in each of these years to £280 million.
- 4.33. NHS England held a four-week public consultation, between 3 and 31 October 2014, on proposed changes to the operation of the Cancer Drugs Fund. Following the consultation, on 12 November 2014 NHS England published revised Standard Operating Procedures for the Cancer Drugs Fund.<sup>49</sup> The revised procedures include the introduction of an explicit cost element to the prioritisation process to try and drive down prices and improve value through the Fund.

### Molecular diagnostics

- 4.34. NHS England's *Five Year Forward View* described how the health and care system will act as a catalyst to accelerate innovation. Better use of diagnostic interventions, including existing molecular pathology services, genetic and genomic testing will reduce variation in provision, improve prediction and prevention of disease, and enable precise diagnosis and personalisation of treatments. NHS England is committed to working with CCGs to establish arrangements for the commissioning of genomic, genetic and molecular pathology services through the newly established Genomic Local Laboratory Hubs to ensure equity of access to meet the needs of defined populations. NHS England will work with CCGs and the Central Laboratory Hubs which will have the gene sequencing capability.
- 4.35. NHS England is working to ensure the appropriate commissioning of other existing diagnostic services that underpin the whole functional genomic pathway. This includes pathology, imaging, physiological diagnostics and endoscopy and to improve outcomes across all episodes of care as part of integrated diagnostic services aligned to clinical pathways. Advice will be made available to commissioners to enable the provision of high quality and innovative provider models. During the course of 2015/16 diagnostic

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<sup>49</sup> <http://www.england.nhs.uk/ourwork/pe/cdf/>

services accreditation will be made more widely available and over time this will be expected to be embedded into commissioning guidance and arrangements.

## Peer review

- 4.36. In 2013/14 the National Peer Review Programme completed the fifth annual round of peer review that comprised self-assessment by individual teams endorsed by the chief executive of the service provider, supported by external verification and risk based peer review visits. The work to ensure sustainability of the programme continued and services that demonstrated previous high performance received less external assessment but maintained their internal governance.
- 4.37. The quality of cancer services in England as a whole continues to improve, and there are indications that quality assurance is becoming more embedded. There are still areas, however, that require further development; in particular those services that have more recently been included in the programme.
- 4.38. The public website *My Cancer Treatment*, that enables patients to have easy access to peer review reports, has been further developed in partnership with Macmillan Cancer Support, and has received a significant increase in number of visitors to the site. The programme continues to move towards a more clinical and patient outcomes focus.
- 4.39. Working with the National Cancer Intelligence Network (NCIN), outcomes data and clinical indicators are used for Clinical Lines of Enquiry and using service profiles produced by NCIN where they exist. The National Cancer Patient Experience Survey also continues to be included as a key indicator for the quality of the service.
- 4.40. The programme now reviews the quality of cancer services for 1,449 tumour Multi-Disciplinary Teams (MDT), along with services for acute oncology, chemotherapy, higher intensity chemotherapy, radiotherapy, children's and teenage and young adult's cancer. The National Peer Review Programme now reviews the quality of 2,153 clinical cancer services and teams.
- 4.41. The national overview shows that some teams and services continue to achieve very high levels of compliance with the measures, with 40% of MDTs achieving compliance of over 90%. This was also the case in the cross cutting services; with 74% of radiotherapy services and 83% chemotherapy services achieving 90% and 64% of the children, teenage and young adults cancer services achieving over 90%.
- 4.42. However, the 2013/14 round of peer review has highlighted some continued challenges. There are still a number of teams that are achieving less than 50% compliance with the measures. Whilst this is a particular concern in relation to acute oncology and cancer of unknown primary where some services have not yet been appropriately established, there are a small number of established services that are also outliers.
- 4.43. Some of these are already being addressed at a local level following the relevant visits and report; others still need to be addressed. 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 of both workforce and throughput of patients.
- 4.44. In 2013/14 the support for networking groups remained a challenge with variable models implemented across the different Strategic Clinical Networks. The National Peer Review Programme, whilst not undertaking review visits to the networking groups, encouraged

continuation of self-assessment based on the outputs of the groups in support of equitable provision of services for their given area.

- 4.45. Completion of the self-assessment has been inconsistent and is indicative of the challenges faced in maintaining the groups within the changing structures.
- 4.46. The programme has been accepted by the Care Quality Commission (CQC) as one of a number of accredited providers of information that will support the Chief Inspector of Hospitals in the inspection programmes. The National Peer Review Programme provides CQC with profile information prior to the visits.
- 4.47. In March 2014 the programme moved to NHS England as part of its specialised commissioning responsibilities. Following the move, NHS England aligned the programme with the ambitions and priorities of specialised commissioning and agreed a programme to include additional services as it did for children and young people's diabetes services and major trauma services in 2013/14.
- 4.48. NHS England is currently reviewing the National Cancer Peer Review programme with a view to considering how its success might be extended into other new areas of specialised commissioning. Regardless of the outcome of this review, cancer peer review will continue to play a critical part in any broader peer review programme considered for introduction.

## Older people with cancer

### Clinical review

- 4.49. The National Cancer Equality Initiative (NCEI) and Pharmaceutical Oncology Initiative (POI) have released a series of reports reviewing the evidence on the benefits and side effects of drug treatment in older people. These will help support informed clinical practice, ensuring that treatment decisions are based on what is most appropriate for the patient and not simply on the basis of a patient's age. *Evidence for the use of cancer drugs to treat older people: A summary of evidence on the tolerability and effectiveness of systemic anti-cancer therapy in older people* (December 2014) provides a short outline of the findings covering breast, kidney and blood cancers.<sup>50</sup>

### NCIN report

- 4.50. In December 2014, NCIN published a report looking at the experiences of older people with cancer, including a wide range of data.<sup>51</sup> The report raised awareness of the patient experience at each stage of the cancer pathway and other factors that can affect outcomes for older people. Improving the experience and outcomes of older people will be a key focus of future work to improve cancer services.

### Understanding attitudes

- 4.51. Macmillan Cancer Support and Age UK, in partnership with NHS England's *call to action*, are developing research to understand the attitudes and perceptions of older people towards cancer.

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<sup>50</sup> <http://www.macmillan.org.uk/Documents/AboutUs/Research/InclusionProjects/use-of-cancer-drugs-to-treat-older-people.PDF>

<sup>51</sup> <http://www.ncin.org.uk/>

## 5. Patient experience and survivorship

### Introduction

5.1. Ensuring patients receive good quality, compassionate care and are well supported through end-of-life care or survivorship is the final but no less important pillar of the Improving Outcomes strategy. In this chapter we provide an update on the latest iteration of the Cancer Patient Experience Survey (CPES), and an update on the National Cancer Survivorship Initiative.

### Cancer Patient Experience Survey (CPES)

5.2. The CPES is the flagship national assessment of patient satisfaction with their cancer treatment. The national CPES 2014 asked over 110,000 cancer patients across the country for their views on their care, with 64% responding.

5.3. The results show improvements in over half of the questions asked compared with the first survey in 2010, with patients reporting positively on areas including feeling they were given enough information, being offered a range of treatment options and being treated with respect and dignity.

5.4. However, the report suggests clear areas for improvement, with many patients feeling that GPs and nurses at their general practice could do more during their cancer treatment and many feeling they were not given enough care from health and social services post discharge.

5.5. Key findings include:

- 89% of patients rated their care as “excellent” or “very good” (compared to 88% in 2013 and 2012. No data for 2010)
- 86% of patients said they were given a choice of different types of treatment (compared to 85% in 2013 and 83% in 2010)
- 89% of patients said they were given the name of a Clinical Nurse Specialist (compared to 88% in 2013 and 84% in 2010)
- 91% of patients said the Clinical Nurse Specialist listened carefully to them and that when they asked important questions they got understandable answers all/most of the time (the same ratings as in 2010, 2012 and 2013)
- 84% of patients said they were always treated with respect and dignity by staff (compared to 83% in 2013 and 2012 and 82% in 2010)
- 59% of patients said they were given enough care and help from health and social services post discharge (compared with 60% in 2013, 61% in 2012 and 60% in 2010)
- 66% of patients said that GPs and nurses at their general practice did everything they could to support them during their cancer treatment (compared with 68% in 2013, 67% in 2012 and 69% in 2010).

- 5.6. In September 2014, Macmillan Cancer Support published *Cancer Patient Experience Survey: Insight Report and League Table* which highlighted the ten most improved trusts between the 2012/13 and 2013/14 surveys.
- 5.7. In response to the results of the survey, NHS Improving Quality (NHS IQ) will launch a pioneering project in 2014 that pairs highly-rated cancer Trusts with Trusts that have potential to improve. This is a drive to reduce national variation in patients' experience of care and raise overall standards. The 'buddying' programme will involve up to 12 Trusts and will be directed at clinical and managerial staff, including directors of nursing and quality, cancer lead nurses and Multi-Disciplinary Teams (MDTs).
- 5.8. NHS IQ is also running events in partnership with Macmillan Cancer Support and NHS England to look at how cancer patient experience data is used by commissioners. It has published an Introductory Guide to Quality Improvement based upon CPES for Cancer Nurses with Macmillan Cancer Support in 2014.
- 5.9. The Cancer Patient Experience Survey again highlighted the link between access to a clinical nurse specialist and a good patient experience. The first UK-wide census of adult specialist cancer nurses was commissioned by Macmillan Cancer Support and results were produced for each country, to help commissioners and workforce planners to understand and address issues and challenges in the cancer nurse workforce. In England, the total reported specialist adult cancer nursing workforce was 3,088 whole time equivalent. This is an increase of 10% since 2011.
- 5.10. Tables showing the best and worst performing Trusts are at Annex D.

## Patient Reported Outcome Measures (PROMs)

- 5.11. *Quality of life of cancer survivors in England: One year on from the 2011 survivorship survey pilot* was published in September 2013.<sup>52</sup> This report was based on the results of a survey following up the initial cohort of patients included in the PROMs pilot in 2011. In general, patients gave very similar answers to the follow-up survey as they had done to the initial 2011 survey, with a small number of respondents slightly less positive than they had been previously.
- 5.12. An analysis of a pilot survey of bladder cancer survivors, collected between January and March 2013, is currently underway, in partnership with the Knowledge and Intelligence Team (South West) PHE. The publication date is yet to be determined.
- 5.13. An analysis of a pilot survey of gynaecological cancer survivors – including cancer of the womb, ovary or cervix – collected between January and March 2014 is currently underway in partnership with the Knowledge and Intelligence Team (East Midlands) PHE and the Site-Specific Clinical Reference Group. In addition, the national colorectal PROMs survey results are awaiting publication.
- 5.14. The Prostate Cancer UK call-out has been awarded - it will cover the whole of the UK, and will take two years to complete. The project aims to gain insight into men's quality of life following a diagnosis of prostate cancer, and will identify what patients feel they need from treatment and care, as well as areas men and families affected by prostate cancer feel could be improved.

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<sup>52</sup> <http://www.quality-health.co.uk/resources/surveys/cancer-survivorship-survey/503-cancer-survivorship-survey-2012-report/file>

## The National Cancer Survivorship Initiative (NCSI)

- 5.15. The National Cancer Survivorship Initiative (NCSI) has set out to understand the numbers, needs, experiences of people living with and beyond cancer, and the most effective service solutions to meet these growing numbers – expected to reach 3.4 million by 2030.<sup>53</sup>
- 5.16. The NCSI recommended four priority areas:
- recovery package
  - consequences of treatment and PROMs
  - stratified pathways of care
  - physical activity.
- 5.17. Discussions have taken place regarding a restructured NCSI jointly led by the Chief Executive of Macmillan Cancer Support and the National Clinical Director for Cancer in NHS England. The governance structure will be revised 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, any future NCSI related work will align with the work of other NHS England Domain teams (particularly Domain 2) and NHS IQ.
- 5.18. To support this work NHS England, in partnership with Macmillan Cancer Support, has established the Living with and Beyond Cancer Programme (LWBC), a two-year programme of work to embed the four priority areas from NCSI into mainstream commissioning. This is being delivered by a Programme Manager and Programme Officer, funded by Macmillan Cancer Support and seconded to NHS England. The programme is working closely with the NHS England Long Term Conditions Programme to align the NCSI Framework with that of the House of Care Long Term Conditions Framework.
- 5.19. Strategic Clinical Networks are working towards embedding the four priorities into commissioning through a range of programmes and the LWBC Programme is working with them and CCGs to progress this.
- 5.20. Boxes 1, 2, and 3 show examples of local activity.

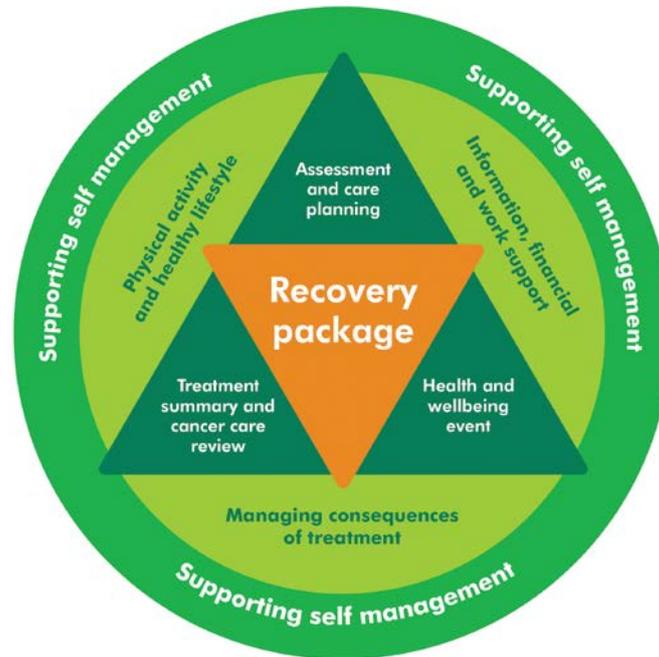
### Survivorship recovery package

- 5.21. Throughout 2014, significant progress has been made in assessment and care planning, specifically with the electronic holistic needs assessment (eHNA). The eHNA is a Macmillan Cancer Support tool that provides people living with cancer an opportunity to record their needs and concerns on an easy to use electronic template, allowing for a focussed discussion with a healthcare professional. This then creates a care plan allowing tailored support to address a patient's needs. In 2013, there were 17 sites in

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<sup>53</sup> 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.

England set up. There are now over 50 and nearly 40 sites actively using the tool. By the end of the year there will be 65 set up and using it, with another 22 planned to go live in 2015.



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- 5.22. Using this tool, there has been a 91% increase in assessments per week over the year to date (as at October 2014), and a 158% increase in the number of care plans. It is predicted that by December 2014 there will have been approximately 8,600 assessments made and approximately 6,400 care plans delivered, but the final figures may well be higher.
- 5.23. Further progress has been made by Macmillan Cancer Support, with refreshed guidance published for treatment summaries and cancer care reviews.

### Financial support

- 5.24. Many people affected by cancer are faced with reduced income and increased expenditure as a result of their diagnosis, leaving more than four out of five an average of £570 a month worse off.<sup>54</sup> Macmillan Cancer Support's Specialist Benefits Advice Service helps cancer patients to understand and access the benefits they could be entitled to, including the Personal Independence Payment (PIP) and the Employment and Support Allowance (ESA). In addition, Macmillan Cancer Support's Financial Guidance Service provides specialist support to help people to understand their financial options and make informed decisions on mortgages, pensions and insurance.

<sup>54</sup> [Cancer's Hidden Price Tag: Revealing the costs behind the illness](#), Macmillan Cancer Support, April 2013:

## Work and cancer

- 5.25. With over 630,000<sup>55</sup> people of working age living with cancer in England, and 99,000<sup>56</sup> new cases diagnosed each year, it's increasingly important that people of working age are supported to remain in or return to work, if that is their wish.
- 5.26. Work may be one of the issues people raise as part of the holistic needs assessment and when developing a care plan. The Macmillan Cancer Support *Work Support Route Guide* helps direct professionals to the right information. In July 2014 Macmillan Cancer Support launched a new programme for employers called *Macmillan at Work*. This is an innovative programme specifically targeting line managers, HR professionals and well-being staff, to help them prepare for the impact of cancer in the workplace. Employers who sign up can access expert training and consultancy and receive their free *Essential Work and Cancer* toolkit. This was followed in autumn 2014 by the *Your Rights at Work* campaign to increase awareness amongst people affected by cancer that they are protected from unfair treatment by the Equality Act 2010 (or the Disability Discrimination Act in Northern Ireland).

### Box 1 - The Transforming Cancer Services for London programme

*For 2015/16, the Transforming Cancer Services for London programme, the regional Cancer Commissioning Board and the London Clinical Commissioning Group Chief Officers have agreed to include a number of Living With and Beyond Cancer commissioning intentions in all 29 acute providers' contract negotiation rounds. The commissioning intentions consist of three core deliverables: implementing the recovery package which consists of holistic needs assessments (HNAs) and care plans, treatment summaries and health and well-being events for patients; consequences of treatment pathways (for pelvic radiation disease, sexual dysfunction and lymphedema) and stratified follow up (in breast, colorectal and prostate cancer pathways). Progress will be monitored closely and followed up in acute Trust Clinical Quality Review Groups as necessary.*

## Consequences of cancer and its treatment

- 5.27. A failure to identify and manage consequences of treatment effectively can compromise survival, quality of life, recovery, patient experience and patient safety.
- 5.28. In 2014, much progress has been made in raising awareness of the need to better manage the consequences of cancer and its treatment. *Throwing Light on the Consequences of Cancer and its Treatment*<sup>57</sup> brought together, for the first time, evidence on the prevalence of consequences of treatment, which has proved to be successful in 2014 in raising the profile of consequences of treatment amongst patients and professionals. Driven by feedback from patients, a national 'Pelvic Cancer Project' was set up to focus on bowel, sex and urinary problems after treatment of pelvic cancers. A randomised controlled trial published in *The Lancet* has demonstrated the

<sup>55</sup> *Cancer Prevalence in the United Kingdom: estimates for 2010*, Maddams J, et al. *BJC* 2009. 10:541-547. Working age estimates are for 18-64 years, assuming 1% of people living with cancer are under 18.

<sup>56</sup> [Cancer Statistics Registrations, England, 2011](#), Office for National Statistics. (Accessed August 2013)

<sup>57</sup> [Throwing light on the consequences of cancer and its treatment](#), Macmillan Cancer Support, July 2013:

benefit of algorithm-based clinical care for bowel problems after pelvic radiotherapy.<sup>58</sup> A service improvement project in Manchester and London supported by the ‘Pelvic Cancer Project’ has demonstrated that management is possible by gastroenterologists or nurses using the algorithm<sup>59</sup> and clinical guidance.<sup>60</sup> A partnership programme with the British Society of Gastroenterology to roll out this approach is now involving over 30 hospitals.

- 5.29. More specifically, a number of resources have been developed to improve education and awareness for professionals, such as the publication of:
- *A Competence Framework for Nurses: Caring for Patients Living With and Beyond Cancer*<sup>61</sup>
  - *Guidance on Long Term Consequences of Treatment for Gynaecological Cancer. Part 1 Pelvic Radiotherapy*<sup>62</sup>
  - *Guidance: The Practical Management of the Gastrointestinal Symptoms of Pelvic Radiation Disease.*<sup>63</sup>
- 5.30. Additionally, to ensure professionals identify people at risk of consequences of treatment, simple versions of PROMs questions are being promoted for pelvic radiation disease that professionals can use to encourage patients to talk about problems.<sup>64</sup>
- 5.31. In 2014, NICE also increased its coverage of consequences of treatment in its 2014 NICE Prostate Cancer updated guideline.<sup>65</sup> The need for specialists such as gastroenterologists and dieticians to be part of the MDT to help men with bowel problems after prostate radiotherapy was given ‘Key priority for implementation’ status. This will help identify and support patients earlier, through local pathways for care for the consequences of treatment, with referral to specialist services where needed. For example, the *Five Year Cancer Commissioning Strategy for London* requires CCGs and providers to establish care pathways for managing consequences of treatment such as pelvic radiation disease, lymphoedema and sexual difficulties.<sup>66</sup>

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<sup>58</sup> [Algorithm-based management of patients with gastrointestinal symptoms in patients after pelvic radiation treatment \(ORBIT\): a randomised controlled trial](#) Andreyev et al. The Lancet 2013 382: 2084-2092

<sup>59</sup> [Guidance: The practical management of the gastrointestinal symptoms of pelvic radiation disease](#) Andreyev et al. Frontline Gastroenterology 2014

<sup>60</sup> [Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result of treatment for cancer](#) Andreyev et al. Gut 2012 61:179-192

<sup>61</sup> [www.macmillan.org.uk/competenceframework](http://www.macmillan.org.uk/competenceframework) [PDF]

<sup>62</sup> [www.macmillan.org.uk/prdgynaeguidance](http://www.macmillan.org.uk/prdgynaeguidance)

<sup>63</sup> [www.macmillan.org.uk/prdgastroguidance](http://www.macmillan.org.uk/prdgastroguidance)

<sup>64</sup> <http://www.prda.org.uk/sites/default/files/resources/PRDA-Fact-Booklet.pdf>

<sup>65</sup> <http://www.nice.org.uk/guidance/cg175>

<sup>66</sup> <http://www.england.nhs.uk/london/2014/04/15/tackle-cancer/>

### Box 2 - The publication of A Competence Framework for Nurses: Caring for Patients Living With and Beyond Cancer<sup>67</sup>

*Written by Macmillan Cancer Support's Consequences of Cancer and its Treatment (CCaT) community of influence on consequences of cancer and its treatment<sup>68</sup>, and endorsed by the Royal College of Nursing and the UK Oncology Nursing Society (UKONS), this is the first ever competence framework to encourage nurses to acquire new skills and to embrace innovative ways of managing cancer as a long-term condition in adults. Over 1,700 copies have been distributed (as at September 2014).*

*"What an excellent document. I have ordered hard copies for all the CNSs and would love to see this as a standard across the trust for all cancer specialist nurses." Lead Cancer Nurse, NHS Trust*

### Stratified pathways of care

- 5.32. Supporting patients to manage their own health and wellbeing can help meet currently unmet needs and reduce demand on services, where appropriate. Throughout 2014, 'Stratified cancer pathways: redesigning services for those living with or beyond cancer'<sup>69</sup> has proved to be the most useful resource for redesigning and implementing follow-up pathways for people with breast, colorectal and prostate cancer. The Southampton redesign project has followed almost 1,000 patients in the first year of follow-up to identify the characteristics of patients and their health and quality of life outcomes in the context of the real life clinical stratification process. The results of this research are due to be published in the coming months and will add detailed evidence around how to redesign follow-up pathways successfully.
- 5.33. Additionally *Innovation to implementation: Stratified pathways of care for people living with or beyond cancer - A how to guide*<sup>70</sup> is being used by service development teams with partnership organisations to implement stratified cancer pathways effectively across the UK.

### Box 3 - South Yorkshire, Bassetlaw and North Derbyshire Survivorship Programme

*Redesigning the colorectal survivorship pathway through a partnership involving the South Yorkshire Commissioning team, seven CCGs, Macmillan Cancer Support, Age UK, primary and secondary care providers and Monitor Deloitte. Pathways are stratified and new cancer workforce models are being tested to bring care closer to home and improve the patient experience. Professionals are supporting people to self-manage, using individualised treatment plans and enabling patients to make decisions about their on-going treatment and management. These changes are resulting in more efficient care through better focused commissioning, communication and co-ordination. Evaluation is due to be completed in March 2015.*

<sup>67</sup> [www.macmillan.org.uk/competenceframework](http://www.macmillan.org.uk/competenceframework) [PDF]

<sup>68</sup> <http://www.macmillan.org.uk/Aboutus/Ourresearchandevaluation/Ourresearchpartners/CCaT.aspx>

<sup>69</sup> <https://www.nice.org.uk/savingsAndProductivityAndLocalPracticeResource?ci=http%3a%2f%2ffarms.evidence.nhs.uk%2fresources%2fQIPP%2f1029456%3fniceorg%3dtrue>

<sup>70</sup> <http://www.ncsi.org.uk/wp-content/uploads/howtoguide.pdf>

## Physical activity

- 5.34. Physical activity improves quality of life and clinical outcomes including consequences of treatment (e.g. fatigue, heart damage, bone thinning) and comorbidities. It can also reduce the risk of cancer recurrence or getting a second primary cancer.<sup>71</sup> The approach Macmillan Cancer Support is taking is an amendment of the NHS physical activity care pathway *Let's Get Moving*<sup>72</sup>, updated with NICE Public Health Guidance on behaviour change.<sup>73</sup> This embeds the service into both primary and secondary care with health care professionals raising the importance of physical activity to patients. They are then offered a support service with behavioural change counselling for one year, based in the community.
- 5.35. A key part of the pathway is ensuring participants are offered a wide range of options to become active. One of the options that people can choose is walking, and Macmillan Cancer Support have partnerships with *Walking for Health* in England and *Paths for All* in Scotland.
- 5.36. Additional work on promoting physical activity is being carried out by charities such as Breast Cancer Care.
- 5.37. In 2014, Macmillan Cancer Support published a revised version of *Walking Works* specifically aimed at health professionals, *Walking Works; Making the case*, to encourage greater uptake of walking as a physical activity to reduce the burden of long-term health conditions on the NHS.<sup>74</sup> These services are developed in partnership with local decision makers including commissioners, public health, and leisure providers. Macmillan Cancer Support works with 40 sites in the UK testing this approach across the cancer care pathway, with a national evaluation commissioned that will first report in 2016. Six of these sites are being delivered in partnership with Sport England.

## Children and young people

- 5.38. A number of new resources and a summary report are available in relation to children and young people.<sup>75</sup>
- 5.39. The children, teenager and young people survivorship work is focussed on testing models of care to identify principles and prototype models for further testing.
- 5.40. In 2014 survivorship activities have focused on treatment summaries, care plans and tools to implement supported self-management. The group has had input into the Generic Transition Service Specification as part of the expert reference group supported by NHS IQ at the request of the National Clinical Director for Children, Young People and Transition to Adulthood. Both the children and young people and teenager and young people Clinical Reference Groups have highlighted transition in the service specifications.

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<sup>71</sup> <http://livinglonger.dh.gov.uk/conversations/macmillan-second-cancers/>

<sup>72</sup> [Let's Get Moving. Commissioning Guidance. A physical activity care pathway](#), Department of Health 2012.

<sup>73</sup> [Behaviour change: individual approaches](#), NICE 49 2014.

<sup>74</sup> [http://www.macmillan.org.uk/Documents/AboutUs/Health\\_professionals/Physicalactivity/Walking-Works-professionals-version.pdf](http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/Physicalactivity/Walking-Works-professionals-version.pdf)

<sup>75</sup> <http://www.nhsiq.nhs.uk/improvement-programmes/acute-care/children-and-young-peoples-survivorship.aspx>

## End of life care

- 5.41. The End of Life Care Strategy is now six years old 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.
- 5.42. Since April 2013 NHS England and CCGs have been responsible for commissioning end of life care services. NHS England recently published *Actions for End of Life Care*, which outlined the progress it has made in improving end of life care. NHS England proposes to publish an updated ambition for end of life care, produced in partnership with stakeholders and system partners, in 2015.

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

- 5.43. 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). The latest data for 2013-14 shows DiUPR at 44.7%<sup>76</sup> an improvement of 0.8%.

### National survey of bereaved people (VOICES)

- 5.44. In July 2014, the ONS published the third annual VOICES survey of bereaved people. This showed that:
- overall quality of care has not changed significantly between 2011, 2012 and 2013
  - quality of care was rated significantly lower for people who died in a hospital compared to people dying at home, in a hospice or care home
  - for those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012
  - the dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013
  - pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%)
  - only half of people (50%) who express a preference to die at home actually die at home.

### Electronic palliative care coordination systems

- 5.45. NHS IQ's *Transforming End of Life Care in Acute Hospitals* programme is working on the wider implementation of electronic palliative care registers (EPaCCs). These can provide instant access to key information about end of life care patients to all health professionals with a need to see it. NHS IQ has set an ambition to achieve a 70% roll out of EPaCCs by 2015, supported through the introduction of a new information standard for use in the NHS.

### Palliative Care Funding Review

- 5.46. The 2011 *Independent Palliative Care Funding Review*<sup>77</sup> reported that “there is a stunning lack of good data surrounding costs for palliative care in England.” In response

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<sup>76</sup> ONS mortality data

to the recommendations of the Review, the Department of Health set up eight pilots to collect a range of data on palliative care and to test the review's recommendations. The pilot phase was completed in March this year.

- 5.47. NHS England has analysed these data, and has proposed a set of currencies for end of life care. NHS England is currently engaging with stakeholders and the public, with the intention of publishing the final draft currencies by the end of 2014.
- 5.48. Further development of a per-patient funding system for palliative care will be based on this and further work with local NHS organisations testing these currencies in 2015-16.

### Liverpool Care Pathway

- 5.49. The independent review of the Liverpool Care Pathway (LCP) published its report in July 2013. The panel made 44 recommendations, including that the LCP be phased out.
- 5.50. The LCP was succeeded by a new and very clear approach in July backed by 21 national organisations, based on 5 priorities of care for the dying person. The Department expects the NHS to follow these clear principles and the Care Quality Commission will be checking against the new approach as part of its new inspection regime

### Free social care at the end of life

- 5.51. Following on from the 2012 *Care and Support White Paper*<sup>78</sup>, DH has been working with leading stakeholders on the issue of free social care for patients at the end of their lives. The DH is currently working with stakeholders, using data collected by the palliative care funding pilots, and wider sources of evidence, to build a cost-benefit analysis of this policy.

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<sup>77</sup> <https://www.gov.uk/government/publications/independent-palliative-care-funding-review>

<sup>78</sup> <https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support>

## Annex A – Progress towards saving 5,000 lives

In *Improving Outcomes: A Strategy for Cancer* (IOSC), we set an ambition to save an additional 5,000 lives per year by 2015. We face a number of challenges in assessing progress against this goal. We are unable to compare our progress directly to other countries in Europe to assess whether we have managed to close the gap, as the Eurocare data on which these original comparisons are based are currently only available up to the year 2007. We can therefore only look at our own performance over the course of the last few years and make an assessment of our progress over that span.

In addition, there is a clear difficulty in attempting to assess progress to date from a fixed point such as 2010. The ONS publishes estimates of one- and five-year survival for the 21 most common cancers every year, broken down by age. The most recent available data are for patients diagnosed in 2008-2012, followed up to 2013. As survival estimates are reported over a range of years, it is difficult to say at what point during that range improvements have been made. For example, the most recent published survival estimates are for patients diagnosed from 2008-2012 and followed up to 2013, and it is impossible to say whether any improvement in the estimated five-year survival for these patients is due to earlier diagnosis in 2008, or perhaps better treatment in 2011. It is therefore not possible to identify every additional survivor who may have benefitted from a change made after the publication of IOSC in early 2011.

Making an assessment of progress towards the 5,000 lives target therefore requires some compromises. In order to produce as simple a comparison as possible, we aim to compare the cohort of patients diagnosed immediately before the publication of IOSC (2006-2010) to the cohort diagnosed immediately after the publication of IOSC (2011-2015). This estimate will not take into account any potential impact of IOSC on patients diagnosed before 2011, who may still have benefitted from changes introduced after 2010.

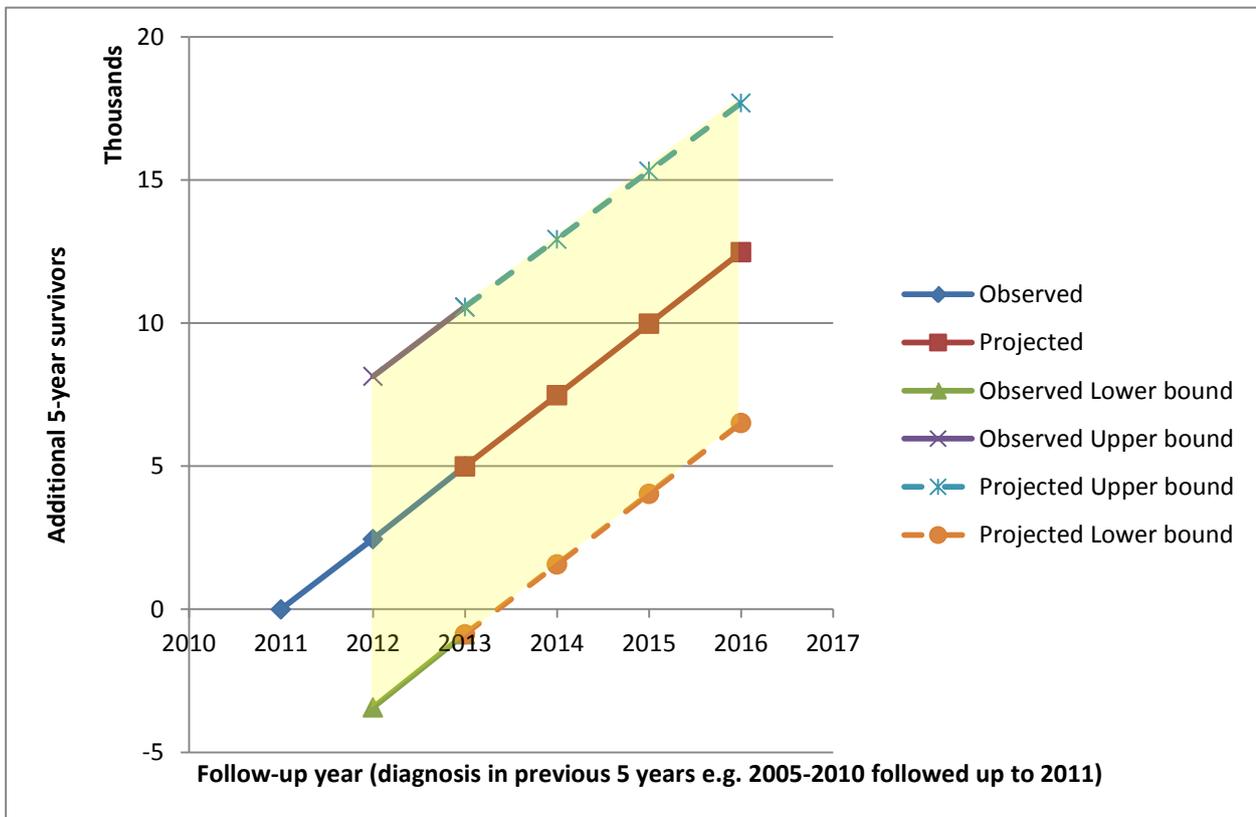
Clearly, we do not yet have survival data for the cohort of patients diagnosed from 2011-2015. However, we do have data for the cohorts 2007-2011 and 2008-2012. Using these most recent available data, five-year survival estimates for each cancer and each age group were projected linearly to produce an estimate of the survival rate expected for patients diagnosed from 2011-2015. Although we have reservations about using such a short series of data to project forwards in time, in 2011 the methodology for calculating survival was changed to better take account of background mortality. We are therefore unable to use a longer time series to produce this estimate. In addition, as we are only forecasting a relatively short distance ahead, we are relatively confident that future survival estimates will not significantly diverge from the trend we observe. There are more complex and potentially accurate methods of estimation that may be possible with more time. However, as a guide to our progress in achieving this ambition, we feel this methodology provides a reasonable estimate.

Using these survival estimates, and keeping incidence for each cancer and age group constant at the level seen in the 2006-2010 cohort to avoid simply counting the effect of increasing incidence, we estimate that on average 6,500-17,500 more patients per year, with a best estimate of 12,000 more patients per year, diagnosed from 2011-2015 will survive their cancer for five years than the cohort of patients diagnosed from 2006-2010. This broad range arises because the margin of error given on the calculated survival estimates is comparable in size to the year-on-year increase in survival. In order to create this range, we have used the 95% confidence intervals calculated by the ONS, and have projected these forwards to the 2011-2015 cohort in the same way as the central estimate. The maximum number of lives saved is

therefore calculated by comparing the lower confidence interval for the 2006-2010 cohort with the projected upper confidence interval for the 2011-2015 cohort. The minimum estimate of the number of lives saved has been calculated by comparing the upper confidence interval for the 2006-2010 cohort with the lower confidence interval for the 2011-2015 cohort.

This reflects a continuing trend in improving cancer survival estimates. Five-year survival for colorectal cancer improved from 54.8% for men diagnosed from 2006-2010, to 58.0% for men diagnosed from 2008-2012. Survival estimates for women diagnosed with colorectal cancer improved from 56.2% to 58.3% over the same span. Five-year survival estimates for women diagnosed with breast cancer have improved from 84.3% to 85.8%. Although these improvements are mostly of the order of 1-2 percentage points per year, when applied to the large number of people diagnosed with cancer each year, they represent a significant improvement to the lives of thousands of people.

**Figure 3 Estimated additional annual five-year survivors**



We urge caution in the interpretation of these projections, and there are three key caveats to make clear:

Firstly, this figure is a projection and is intended simply as an indicative figure to suggest the scale of the improvement since 2010.

Secondly, this estimate can unfortunately tell us nothing about our improvement relative to the best countries in Europe. Although the initial research from which the 5,000 lives ambition stemmed found that the gap from England to the best countries in Europe was roughly 10,000 lives per year, this was based on survival estimates for the cohort diagnosed from 1995-1999, and this analysis has not yet been repeated with more recently available data.

Thirdly we do not claim that all of the improvement in survival since 2011 is due to initiatives in IOSC. The scale of year-on-year improvement is broadly similar before and after IOSC was published, and although we do believe that renewing a strategic focus on cancer is an important

factor in continuing to drive these improvements, a huge number of factors can influence cancer survival estimates.

## Annex B – Survival by Stage at Diagnosis

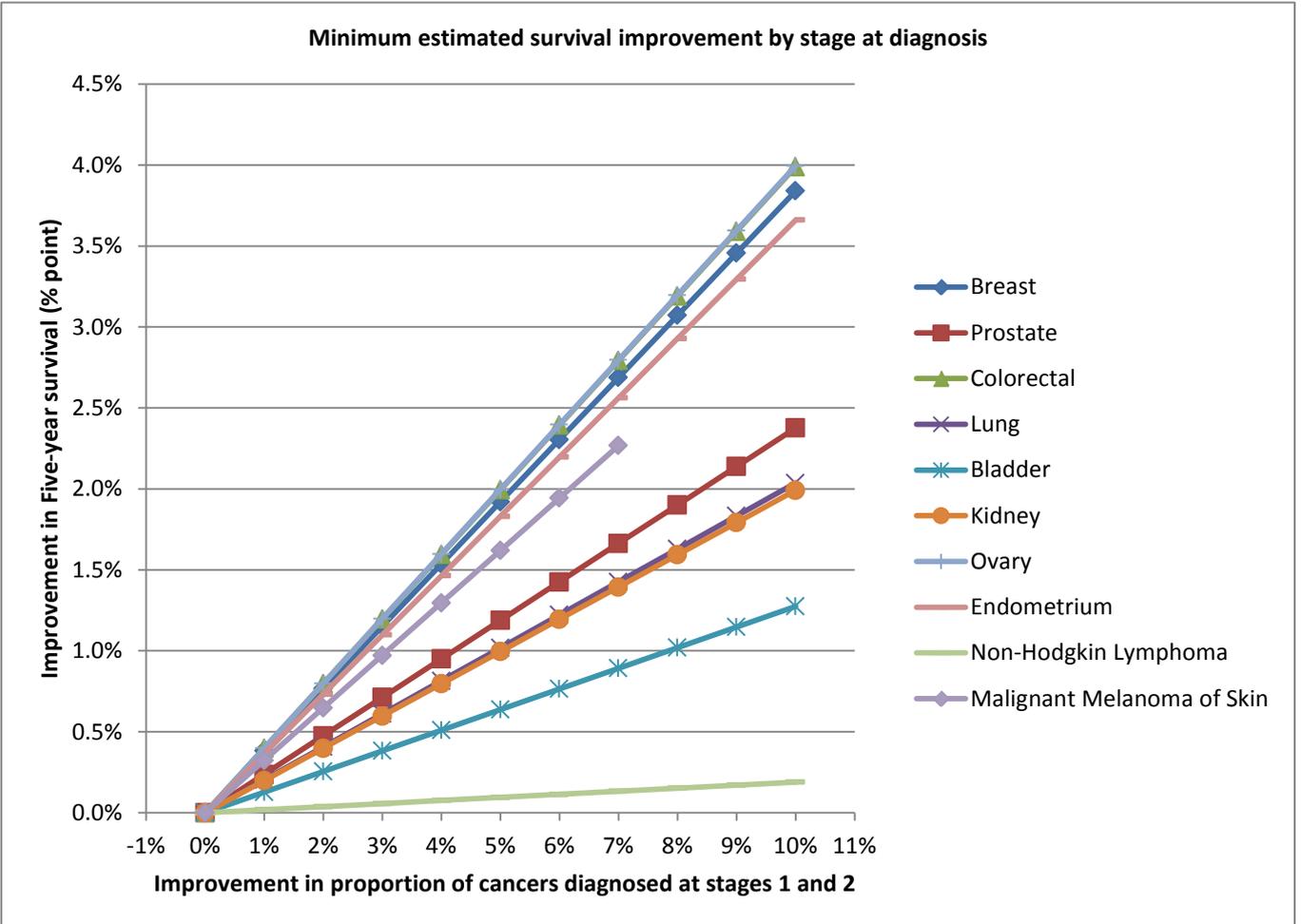
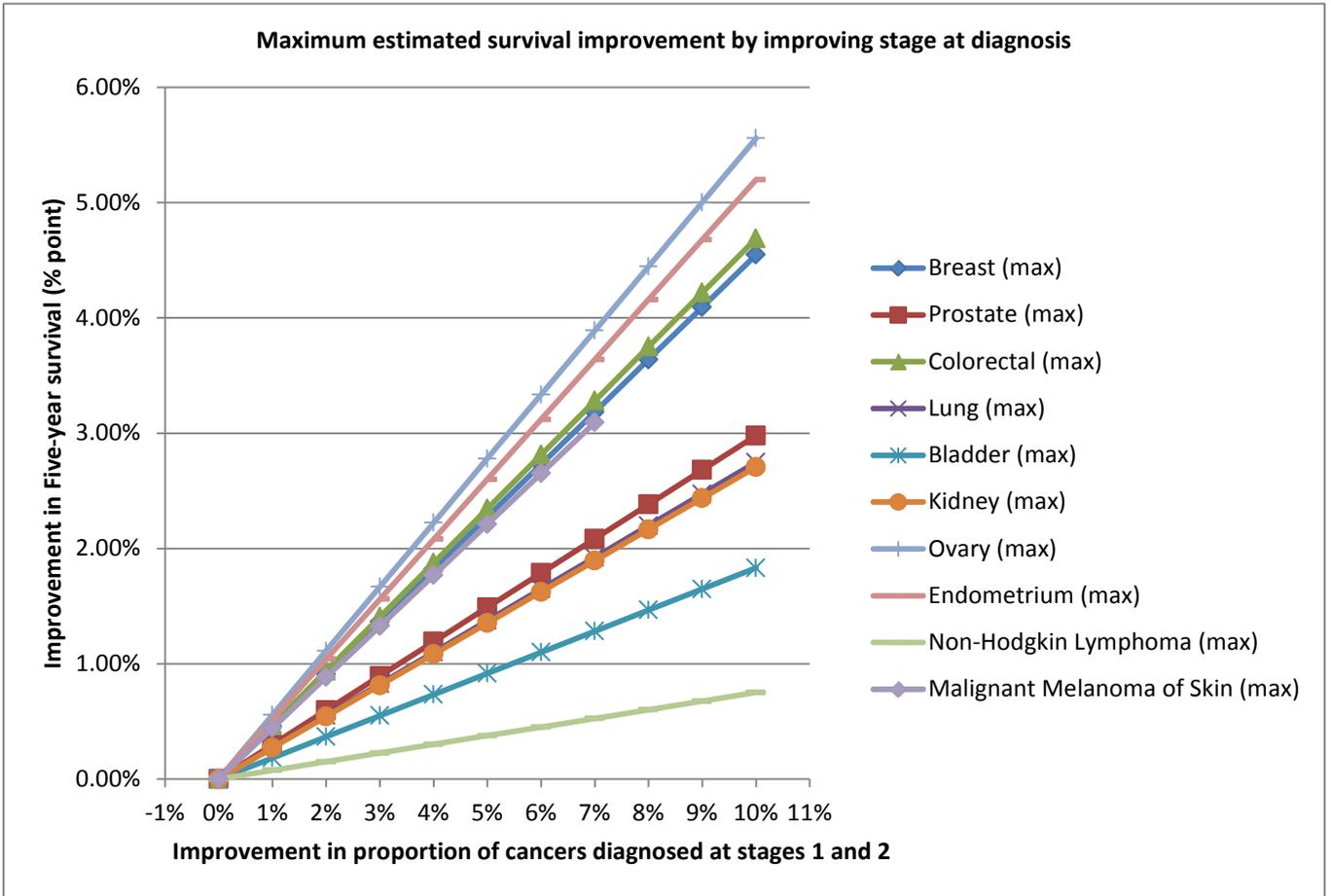
The Department of Health and NHS England have together updated previous analysis to estimate the improvement in five-year survival estimates that would be possible with a significant shift in stage at diagnosis. This work updates the analysis that featured in the third annual report on *Improving Outcomes*, using the latest available 'all England' data.

This work is still relatively crude, and is not intended to provide an accurate assessment of the impact of stage at diagnosis on survival estimates. However, it does provide an indication of the scale of the potential benefits of earlier diagnosis.

The analysis looked at the ten most common cancers in England, and used incidence by stage at diagnosis statistics for the whole of England in 2012. We also used one-year survival by stage at diagnosis for cancers diagnosed in England in 2012. As five-year survival requires a longer lead-time, and high-quality staging data for the whole country has only recently become available, estimates of five-year survival by stage at diagnosis for cancers diagnosed from 2006-2008 in the East of England were used. A 10% shift from cancers diagnosed at stages 3 and 4 to stages 1 and 2 was modelled. Again, this shift is chosen simply to demonstrate the potential impact of a shift in stage rather than to reflect an expected change. As the proportion of cancers of unknown stage was relatively high, these were excluded from the analysis.

To reflect the uncertainty inherent in analysis of this kind, we have reported the results as a range. We estimate that a shift from stages 3 and 4 to stages 1 and 2 of 10% of cancers would lead to an improvement of between 3.4% and 4.4% in five-year survival estimates. To put this in context, this represents between 7,000 and 9,000 additional people surviving their cancer for five years or more each year.

Achieving earlier diagnosis is already a core element of our strategy, but this analysis reinforces the huge improvements in survival which are possible if we diagnose cancer earlier, at a stage at which it is more likely to be possible to treat it effectively. Work is ongoing to refine this model and understand better where the greatest gains are to be made in early diagnosis.



Percentage point increase in proportion of cancers diagnosed at stages 1 and 2	Improvement in 5-year survival % (maximum)										
	Cancer site	0%	1%	2%	3%	4%	5%	6%	7%	8%	9%
Breast	0.0	0.5	0.9	1.4	1.8	2.3	2.7	3.2	3.6	4.1	4.5
Prostate	0.0	0.3	0.6	0.9	1.2	1.5	1.8	2.1	2.4	2.7	3.0
Colorectal	0.0	0.5	0.9	1.4	1.9	2.3	2.8	3.3	3.8	4.2	4.7
Lung	0.0	0.3	0.5	0.8	1.1	1.4	1.6	1.9	2.2	2.5	2.7
Bladder	0.0	0.2	0.4	0.5	0.7	0.9	1.1	1.3	1.5	1.6	1.8
Kidney	0.0	0.3	0.5	0.8	1.1	1.4	1.6	1.9	2.2	2.4	2.7
Ovary	0.0	0.6	1.1	1.7	2.2	2.8	3.3	3.9	4.4	5.0	5.6
Endometrium	0.0	0.5	1.0	1.6	2.1	2.6	3.1	3.6	4.2	4.7	5.2
Non-Hodgkin Lymphoma	0.0	0.1	0.2	0.2	0.3	0.4	0.5	0.5	0.6	0.7	0.8
Malignant Melanoma of Skin	0.0	0.4	0.9	1.3	1.8	2.2	2.7	3.1	N/A <sup>79</sup>	N/A	N/A

Percentage point increase in proportion of cancers diagnosed at stages 1 and 2	Improvement in 5-year survival % (minimum)										
	Cancer site	0%	1%	2%	3%	4%	5%	6%	7%	8%	9%
Breast	0.0	0.4	0.8	1.2	1.5	1.9	2.3	2.7	3.1	3.5	3.8
Prostate	0.0	0.2	0.5	0.7	1.0	1.2	1.4	1.7	1.9	2.1	2.4
Colorectal	0.0	0.4	0.8	1.2	1.6	2.0	2.4	2.8	3.2	3.6	4.0
Lung	0.0	0.2	0.4	0.6	0.8	1.0	1.2	1.4	1.6	1.8	2.0
Bladder	0.0	0.1	0.3	0.4	0.5	0.6	0.8	0.9	1.0	1.1	1.3

<sup>79</sup> The proportion of malignant melanomas with recorded stage currently diagnosed at stages 1 and 2 is >92%, and so it is not possible to increase

Percentage point increase in proportion of cancers diagnosed at stages 1 and 2	Improvement in 5-year survival % (minimum)										
	0.0	0.2	0.4	0.6	0.8	1.0	1.2	1.4	1.6	1.8	2.0
Kidney	0.0	0.2	0.4	0.6	0.8	1.0	1.2	1.4	1.6	1.8	2.0
Ovary	0.0	0.4	0.8	1.2	1.6	2.0	2.4	2.8	3.2	3.6	4.0
Endometrium	0.0	0.4	0.7	1.1	1.5	1.8	2.2	2.6	2.9	3.3	3.7
Non-Hodgkin Lymphoma	0.0	0.0	0.0	0.1	0.1	0.1	0.1	0.1	0.2	0.2	0.2
Malignant Melanoma of Skin	0.0	0.3	0.6	1.0	1.3	1.6	1.9	2.3	#N/A	#N/A	#N/A

## Annex C – *Be Clear on Cancer* evaluation

Evaluation of the cancer awareness campaigns is a comprehensive ongoing programme, comprising measurements from key stages of the patient pathway. A variety of different information is used, including (but not limited to) assessments of cancer awareness levels, attendances to GP practices, levels of urgent referrals and numbers of cancers diagnosed. Some of the information required takes longer to collate and analyse but gradually over time, when combined together, the metrics build up a detailed picture of potential campaign effects.

### National lung cancer (first and second reminder campaigns)

The first national lung campaign ran from 8 May until the end of June 2012. It was evaluated with positive results and reported in last year's report. More detailed results are discussed in Ironmonger *et al.*<sup>80</sup> Since then, two further reminder campaigns have run from 2 July to 11 August 2013 and again from 10 March until the end of April 2014.

Impact from these reminder campaigns is still being assessed. However, initial results demonstrate an overall, upward trend in the number of urgent GP referrals for suspected lung cancer from January 2012 to May 2014. Increases during the campaign periods were greater in women than in men for both reminder campaigns: for the first reminder there was a 35% increase in the number of referrals for women and a 26% increase for men, when comparing July to September 2013 with July to September 2011. 2011 is used as a comparator due to the first national campaign running in late spring 2012. The second reminder campaign showed smaller increases of 7% for men and 9% for women, comparing March to May 2014 with March to May 2013.

The first reminder campaign does not appear to have had an impact on the number of lung cancer diagnoses resulting from an urgent GP referral for suspected lung cancer or the conversion rate in July to September 2013, or on the number of lung cancer diagnoses recorded in the cancer waiting times database or the detection rate in August to October 2013. The results for detection and conversion rate for the second reminder campaign are not yet available.

To date, the results suggest that both reminder campaigns may have resulted in small additional increases in referrals for suspected lung cancer and may have reinforced the key messaging from first national campaign. As more data becomes available on the second lung reminder campaign, this will be explored in more detail.

For the first national lung campaign, as previously reported there was an increase in lung cancers diagnosed, along with evidence of a stage shift and increase in resection rate for patients diagnosed during the months around the campaign compared with the same time in the previous year. Additional data (a proxy measure from Hospital Episode Statistics (HES)) indicate no clear pattern in the proportion of cancers diagnosed after an emergency presentation in the months around and immediately following the national campaign. However, there was a statistically significant decrease in the proportion a few months later in the year; further investigation would be required to understand whether this could be a delayed impact of diagnosing more people earlier around the time of the campaign.

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<sup>80</sup>Ironmonger et al, *BJC*, in press, doi:10.1038/bjc.2014.596

## National bowel cancer campaign

Further evaluation of the 2012 national bowel cancer campaign has shown there was evidence of a statistically significant increase in the number of bowel cancers diagnosed following the launch of the first national bowel campaign (using data from the Cancer Analysis System). An initial analysis of staging data found no evidence of an increase in the number of bowel cancers diagnosed at an early stage following the campaign. However, there was a statistically significant decrease in the proportion of bowel cancers diagnosed following an emergency presentation for the two months after the campaign (April and May 2012) compared with the same period in the previous year, using a proxy measure via HES. Considering survival is worst for patients who present via an emergency<sup>81</sup>, this is promising preliminary evidence to suggest a positive impact of the campaign on cancer outcomes.

## National 'blood in pee' campaign

A decision was taken to run a further blood in pee reminder campaign in October and November 2014. This decision was made based on the results from the evaluation of the first national campaign which ran during the same period in 2013.

The results received to date for the first campaign demonstrates increasing awareness of blood in pee as symptom, with seven in ten (72%) of those aware of cancer symptoms advertising, mentioning blood in pee as a cancer symptom seen or heard about in the last few months. This is compared with 23% pre-campaign. Also, over two in five people spontaneously mentioned blood in pee as a symptom of kidney or bladder cancer (44% up from 27% pre-campaign). Confidence in the knowledge of signs and symptoms of bladder/kidney cancer also increased significantly, going from 28% pre campaign to 41% post campaign (men: 25%-37%, women: 30%-45%). Interestingly, men (71%) were more likely than women (61%) to find the advertising relevant and similarly more men (48%) than women (43%) felt it told them something new.

When looking at the impact of the first national blood in pee campaign on referrals into secondary care, there is evidence of an increase in the number of referrals for suspected urological cancers during the campaign period, and some evidence that this campaign may have had a sustained impact. In England, there was a 26% increase in the number of urgent GP referrals for suspected urological cancers from October to December 2012 to October to December 2013. By age, the increase in number of urological referrals ranged from 19% (aged 80 and over) to 37% (aged under 50). There were smaller percentage increases for men (24%) than for women (31%), although this may be affected by the inclusion of suspected prostate cancers in this referral pathway. For January to April 2014, there was a 23% increase in the number of urgent GP referrals for suspected urological cancers, in England compared to January to April 2013.

From October to December 2012 to October to December 2013, nationally, the number of bladder, kidney and urological cancer diagnoses resulting from an urgent GP referral for suspected urological cancers increased by 8.2%, 22% and 14% respectively, with larger increases for males than females. For the same period, the national conversion rate decreased by 0.6 percentage points for bladder cancers and 1.7 percentage points for urological cancers. There was no significant change in the kidney cancer conversion rate for England.

From November 2012 to January 2013 to November 2013 to January 2014, the number of kidney cancers recorded in the cancer waiting times database increased nationally by 12% and the number of urological cancers increased by 10%. There was no significant change for

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<sup>81</sup> Ellis-Brookes et al, BJC 2012;107;1220-6

England for bladder cancer diagnoses. From November 2012 to January 2013 to November 2013 to January 2014, the detection rate for urological cancers increased by 2.0 percentage points for England. There were no statistically significant changes in the detection rates for bladder and kidney cancers.

### National breast cancer in women over 70 campaign

A campaign to increase awareness of breast cancer in women over the age of 70 ran from 3 February to 16 March 2014. Pre and post campaign awareness surveys were conducted with women in two age groups (40-69 and those aged 70 or over). Among those aware of cancer advertising, the proportion spontaneously mentioning breast cancer rose significantly from 39% to 59% following the campaign. Specifically, for women in the target group (those aged 70 or over) it rose significantly from 38% to 51% following the campaign. Confidence in knowledge of signs and symptoms of breast cancer also increased significantly following the campaign with the proportion of women claiming to be “very confident” of the symptoms increasing from 19% to 26%. As an awareness campaign, it also impacted on the perceptions of the age groups most likely to develop breast cancer. Most encouraging was the significant increase following the campaign (6% to 18%) in the proportion of women who mentioned women over 70 as being the age group likely to develop breast cancer. Overall the proportion of women mentioning “1 in 3 are aged over 70”, a key message from the campaign, rose significantly from 19% to 24%.

The campaign itself was well recognised with 81% having seen one or more of the advertising channels (TV advertisements; 73%, press advertisements; 41% and the leaflet; 28%). Overall 60% agreed that the advertising would prompt them to talk to somebody close to them about the symptoms to watch out for.

As well as increasing awareness, the national breast cancer in women aged over 70 awareness campaign appears to have resulted in a large increase in referrals in the target age group. For women aged 70 and over, there was a 67% increase in combined breast referrals (including referrals for suspected breast cancer and breast symptom referrals), between February to April 2012 and February to April 2014. This increase in combined breast referrals for women aged 70 and over reflects a 64% increase in referrals for suspected breast cancer and a 75% increase in breast symptom referrals.

In England, the largest increase in referrals was seen for the 70-79 age group, with a 77% increase in combined breast referrals. A larger increase was also seen for women aged 80 and over (50%) than for all the younger age groups.

These increases in referrals appear to have led to an increase in the number of breast cancer diagnoses, with a statistically significant 25% increase in the number of breast cancers diagnosed, following either an urgent GP referral for suspected breast cancer or a breast symptom referral, between February-April 2012 and February-April 2014 for those aged 70 and over. For these women, the total number of breast cancer diagnoses recorded in the cancer waiting times database also appeared to increase following the national campaign, with a significant 31% increase in the number of cancers recorded between March-May 2012 and March-May 2014. Although, for this same period, as the increase in total diagnoses is larger than the increase in diagnoses resulting from urgent referrals, the detection rate decreased significantly by 5 percentage points.

Full evaluation of the Be Clear on Cancer campaign for breast cancer in women over 70 is ongoing and not yet complete. However, some initial interim analysis has also been undertaken to assess the number of women in the target age range self-referring into the breast cancer screening programme during the campaign period. Early preliminary results currently show that for the six weeks in February/March of 2014, during which the campaign ran, a total of 21,607

women self-referred. This was compared to 9,175 women in the equivalent six week period in 2011<sup>82</sup>, when there was no campaign running. There was therefore, a net increase of 12,432 self-referrals. Further detailed work will need to be undertaken to explore this finding in more detail.

### Regional oesophago-gastric campaign

Following evaluation of a local pilot, an oesophago-gastric regional campaign ran in the Tyne-Tees and Border TV regions from 10 February to 9 March 2014.

Awareness of oesophageal cancer symptoms was low before the campaign and the campaign was able to raise awareness of the key symptoms. 87% of those interviewed had seen any cancer advertising/publicity about cancer. 57% of all respondents had seen publicity about cancer symptoms. Of these, when asked to describe the publicity about symptoms, 31% in the pilot region spontaneously mentioned “heartburn” and 24% mentioned “difficulty in swallowing food”. In contrast there were minimal mentions of these symptoms in the control area (and no increase from pre- to post-campaign either). Overall confidence in the knowledge of oesophago-gastric symptoms increased from 25% to 35% for very/fairly confident, with no increase in the control region. The campaign recognition is the highest received to date for a regional pilot, with recognition of the TV advertisement at 69%, the radio advertisement at 20%, the press advertisement at 35% and the campaign leaflet at 19%. 63% agreed that the advertising told them something new, but actions taken by the population as a result of seeing the campaign were still below average.

The regional pilot oesophago-gastric cancer awareness campaign appears to have resulted in a large increase in referrals for suspected upper GI cancers, from February to April 2013 to February to April 2014. Within the regional pilot area, there was a 52% increase in referrals for suspected upper GI cancers, compared to an increase of 17% in the control area. The increase in upper GI referrals was larger for men (63%) than for women (44%), resulting in smaller differences, between men and women, in the number and rate of referrals.

There is no evidence that the regional pilot oesophago-gastric cancer awareness campaign had an impact on the number of diagnosed cancers recorded in the cancer waiting times database, for oesophageal, stomach and upper GI cancers, for March to May 2014, compared to the same months in 2013.

There is some evidence that the regional pilot oesophago-gastric cancer awareness campaign may have had an impact on detection rate for oesophageal, stomach and upper GI cancers, for March to May 2014, compared to the same months in 2013, particularly for those aged in their 60s. For those aged 60-69, there was a statistically significant increase of 29 percentage points in the upper GI cancer detection rate, from 35% to 64%. However, results were based on a relatively small number of upper GI cancer diagnoses, with trends in detection rates demonstrating much inherent variation.

### Regional ovarian campaign

A regional ovarian cancer campaign ran in the Granada TV region from 10 February to 16 March 2014. 87% of women in the pilot region had seen any advertising/publicity about cancer. Of these, when asked to describe the publicity, 35% in the pilot region spontaneously mentioned “bloating” at the post stage (only 2% mentioned this in the control region).

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<sup>82</sup> 2011 is used as a comparator due to there being a 3 year screening round

There was an overall significant increase in confidence in the knowledge of ovarian cancer symptoms, rising from 23% before the campaign to 32% afterwards. There was no increase in the control region. In addition there were encouraging increases in prompted knowledge of a range of symptoms of ovarian cancer symptoms including:

- feeling bloated most days for three weeks or more (significant increase from 25% to 40% saying “definitely”)
- feeling full quickly on a regular basis (significant increase from 32% to 44% saying “probably”)
- persistent stomach pain (significant increase from 48% to 61% saying “probably”).

There were no increases in the control region.

The campaign material was well recognised by 76% of women in the pilot area compared with 41% in the control region. Specifically the TV advertisement was recognised by 71% of respondents, radio by 33%. Strong messaging was achieved, with 79% of women agreeing that the advertising stood out (this is the highest percentage achieved by a regional *Be Clear on Cancer* campaign) and 66% agreeing that the advertising told you something new. Higher levels of action were taken than from other regional pilots with 21% of women who recognised the advertising having made an appointment to see their GP.

Despite the positive cancer awareness feedback, the other initial results for the regional ovarian campaign are less clear. Although we have evidence of an increase in the number of gynaecological referrals made via the two week wait route (24% in the regional pilot area against 16% in the control region) during the relevant campaign period, we have not identified any evidence of impact on the number of cancer diagnoses recorded in the cancer waiting times database or on the detection rate during the pilot.

## Annex D – Best and worst performing Trusts from Cancer Patient Experience Survey

### Which were the top ten most improved Trusts?

Trust	No. of scores significantly worse in 2014	No. of scores significantly better in 2014
The Dudley Group NHS Foundation Trust	0	14
York Teaching Hospital NHS Foundation Trust	1	14
University Hospital of South Manchester NHS Foundation Trust	1	14
Luton and Dunstable University Hospital NHS Foundation Trust	0	13
Mid Essex Hospital Services NHS Trust	0	13
Nottingham University Hospitals NHS Trust	0	13
North Bristol NHS Trust	0	12
Portsmouth Hospitals NHS Trust	1	12
South Devon Healthcare NHS Foundation Trust	0	10
St George's Healthcare NHS Trust	0	10
Sherwood Forest Hospitals NHS Foundation Trust	0	10
Heart of England NHS Foundation Trust	0	10

**The top performing Trusts in 2014**

<b>Trust</b>	<b>No. times in top 20% of Trusts</b>	<b>No. times in bottom 20% of Trusts</b>
South Tyneside NHS Foundation Trust	46	3
Gateshead Health NHS Foundation Trust	45	2
Harrogate and District NHS Foundation Trust	44	0
St Helens & Knowsley Teaching Hospitals NHS Trust	42	1
East Cheshire NHS Trust	41	1
Northumbria Healthcare NHS Foundation Trust	40	1
South Devon Healthcare NHS Foundation Trust	38	1
Queen Victoria Hospital NHS Foundation Trust	38	4
Yeovil District Hospital NHS Foundation Trust	37	2
Luton and Dunstable University Hospital NHS Foundation Trust	36	0

**The poorest performing Trusts in 2014**

<b>Trust</b>	<b>No. of times in bottom 20% of Trusts</b>	<b>No. of times in top 20% of Trusts</b>
Barts Health NHS Trust	49	2
Milton Keynes Hospital NHS Foundation Trust	45	0
Imperial College Healthcare NHS Trust	44	2
Homerton University Hospital NHS Foundation Trust	44	3
Ashford and St. Peter's Hospitals NHS Foundation Trust	42	0
Barking, Havering and Redbridge University Hospital NHS Trust	41	1
Royal National Orthopaedic Hospital NHS Trust	39	4
Royal Free London NHS Foundation Trust	38	2
North Middlesex University Hospital NHS Trust	37	1
King's College Hospital NHS Foundation Trust	37	0

## Annex E – NCIN national analyses published October 2013 to October 2014

<b>Publication Type</b>	<b>Title</b>	<b>Publication date</b>
Report	Outline of uterine cancer in the UK: Incidence, mortality and survival	October 2013
Report	The NAEDI/Cancer Networks Supporting Primary Care Programme 2012 to 2013 [with Durham University]	October 2013
Online tool	Update of the Urology Profiles	October 2013
Data briefing	Uterine cancer in the UK: Overall trends and variation by age	October 2013
Journal publication	Vulval cancer incidence, mortality and survival in England: age-related trends	October 2013
Poster	Segmenting the 2 million: New understanding of people living with cancer [with Macmillan Cancer Support]	November 2013
Poster	Trends in mortality after cystectomy for bladder cancer in England 1998-2010	November 2013
Journal publication	Low dose aspirin and survival in men with prostate cancer: a study using the UK Clinical Practice Research Datalink	December 2013
Journal publication	The rising incidence of anal cancer in England 1990-2010; a population based study	December 2013
Data briefing	Deprivation and blood cancer survival in England: analysis of cancer registration data 2000-2007	December 2013
Online tool	GLOBOCAN 2012 [with the International Agency for Research on Cancer]	December 2013
Data briefing	High procedure volume is associated with improved survival after lung cancer surgery	December 2013
Data briefing	Oral Cavity Cancer: recent survival trends	December 2013
Data briefing	Recent trends in lung cancer incidence, mortality and survival	December 2013
Interactive Spreadsheet	Segmenting the cancer survivorship population in the UK [with Macmillan Cancer Support]	December 2013

Online tool	Update of the Cancer Commissioning Toolkit	December 2013
Report	What cancer statistics are available, and where can I find them?	December 2013
Journal publication	Access, continuity of care and consultation quality: which best predicts urgent cancer referrals from general practice?	January 2014
Workbook & supporting documents	Routes to Diagnosis (2006 to 2010)	January 2014
Data briefing	Routes to Diagnosis: Cancer of Unknown Primary	January 2014
Journal publication	Type 2 diabetes and the risk of mortality among patients with prostate cancer	January 2014
Report	Bone and Soft Tissue Sarcomas - Changes to Pathology Codes in the 4th Edition of the World Health Organisation Classification of Bone and Soft Tissue Sarcomas	February 2014
Data briefing	One-year relative survival rates for pancreatic cancer in Great Britain, 1995-2009	February 2014
Poster	Repeat surgery within 3 months of initial treatment	February 2014
Journal publication	Variation in promptness of presentation among 10,297 patients subsequently diagnosed with one of 18 cancers: Evidence from a national audit of cancer diagnosis in primary care	February 2014
Journal publication	Variation in promptness of presentation among 10,297 patients subsequently diagnosed with one of 18 cancers: evidence from a National Audit of Cancer Diagnosis in Primary Care	February 2014
Poster	How treatment varies by age in older women with breast cancer with no comorbid conditions	March 2014
Journal publication	Incidence of thyroid cancer in England by ethnic group, 2001–2007	March 2014
Report	Quality and completeness of gynaecological cancer data in the NCDR	March 2014
Report	Rare urological cancers	March 2014
Data briefing	Survival of small cell lung cancer patients undergoing surgery in England 1998 – 2009	March 2014

Online tool	Update of the Cancer Commissioning Toolkit	March 2014
Report	Kidney survival by morphological type	April 2014
Data briefing	Penile cancer: age specific analysis	April 2014
Data briefing	Prostate cancer survival (2004-2007)	April 2014
Report	Routes from Diagnosis [with Macmillan Cancer Support]	April 2014
Report	Cancer by Deprivation in England: Incidence, 1996-2010; Mortality, 1997-2011 [with Cancer Research UK]	May 2014
Journal publication	Impact of Bowel Cancer Screening on the Management of Colorectal Cancer	May 2014
Data briefing	Vulval cancer – trends and variations by age	May 2014
Poster	A multicentre audit of post gastroscopy upper gastrointestinal cancer	June 2014
Report	A report from Cancer52 on National Cancer Intelligence Network data on rare and less common cancers	June 2014
Report	Cancer and equality groups: key metrics; 2014 report	June 2014
Poster	Comparisons of TYA cancer mortality rates in the UK with other countries	June 2014
Poster	Cutaneous melanoma in older persons	June 2014
Poster	Diagnostic Imaging and Cancer Survival	June 2014
Poster	Do older people in the UK have higher cancer incidence than those in the Nordic countries	June 2014
Poster	Effect of comorbidity on surgery and survival in lung cancer patients, England	June 2014
Poster	Enhancing intelligence and research through improved data access	June 2014
Poster	Extremity soft tissue sarcoma amputation rates	June 2014
Poster	Factors that affected who received surgery for pancreatic cancer in England, 1998-2009	June 2014
Poster	Four Be Clear on Cancer pilot awareness campaigns - What impact did they have on urgent GP referrals for suspected cancer?	June 2014
Report	Gynaecological Sarcoma Treatment	June 2014

Report	Head & Neck Sarcoma of the Bone and Soft Tissue – Incidence, Survival and Surgical Treatment	June 2014
Poster	Incidence Projections for Upper GI Cancer in the East Midlands	June 2014
Poster	Managing disclosure in health statistics using statistical geographies	June 2014
Poster	Measuring exposure to fluoridated drinking water for 1st Fluoride Monitoring Report	June 2014
Poster	New female breast cancer patient incidence rates	June 2014
Poster	Other cancers diagnosed in female breast cancer patients in England who died in 2008	June 2014
Poster	Routes to Diagnosis: Does it matter when or how a cancer is diagnosed?	June 2014
Poster	Supporting commissioning by making cancer information publically available – Using the Cancer Commissioning Toolkit	June 2014
Poster	Survival from melanoma in England, Northern Ireland and Scotland	June 2014
Poster	Survival in sarcoma patients with pulmonary metastases	June 2014
Poster	The effect of emergency presentation on surgery and survival in lung cancer patients in England 2006-2008	June 2014
Journal publication	Time and deprivation trends in incidence of primary liver cancer subtypes in England	June 2014
Poster	UK cancer survivorship: What the data tell us about the number of children, teenagers and young adults living with and beyond cancer [with Macmillan Cancer Support]	June 2014
Poster	Understanding the burden and characteristics of older people living with and beyond cancer across the UK [with Macmillan Cancer Support]	June 2014
Online tool	Update of the Cancer Commissioning Toolkit	June 2014
Report	What cancer statistics are available, and where can I find them?	June 2014
Data briefing	Anal cancer: rising trends in England	July 2014
Journal publication	Re-organisation of oesophago-gastric cancer services in England and Wales: a follow-up assessment of progress	July 2014

	and remaining challenges	
Data briefing	The characteristics of individuals with colorectal cancer who die rapidly after their diagnosis	July 2014
Data briefing	Trends in five-year survival for teenagers and young adults with cancer in the UK	July 2014
Report	Variation in the uptake of radiotherapy treatment in Teenagers and young adults diagnosed with cancer in England in 2010	July 2014
Report	Cancer survival in England by stage	August 2014
Online tool	Local Cancer Intelligence [with Macmillan Cancer Support]	August 2014
Poster	Is it possible to measure the effect of immigration on cervical cancer incidence?	September 2014
Poster	Skin cancer treatment in England	September 2014
Poster	Update of Excess Winter Deaths in England	September 2014
Online tool	Update of the Cancer Commissioning Toolkit	September 2014
Data briefing	The impact of cancer service guidance on surgical workload volume: head & neck perspective	October 2014
Journal publication	The impact of head & neck cancer service guidance on surgical workload	October 2014

## Annex F – Data tables for figures

**Figure 1 Trend in cancer mortality, ages under 75, in England**

Year	Period of coverage	Age	Indicator value	Lower Confidence Interval	Upper Confidence Interval
2013	1/1/2013 to 31/12/2013	All	141.5	140.4	142.7
2012	1/1/2012 to 31/12/2012	All	144.6	143.5	145.8
2011	1/1/2011 to 31/12/2011	All	147.1	145.9	148.3
2010	1/1/2010 to 31/12/2010	All	147.8	146.7	149.0
2009	1/1/2009 to 31/12/2009	All	150.5	149.3	151.7
2008	1/1/2008 to 31/12/2008	All	153.6	152.4	154.8
2007	1/1/2007 to 31/12/2007	All	155.7	154.5	157.0
2006	1/1/2006 to 31/12/2006	All	157.7	156.5	159.0
2005	1/1/2005 to 31/12/2005	All	159.8	158.6	161.1
2004	1/1/2004 to 31/12/2004	All	162.5	161.2	163.8
2003	1/1/2003 to 31/12/2003	All	165.8	164.5	167.1

**Figure 2 Under 75 mortality rates from cancer for most and least deprived population deciles (England)**

Year	Deprivation decile									
	Most deprived	2	3	4	5	6	7	8	9	Least deprived
2009	220.3	190.5	173.8	164.9	153.0	138.6	134.3	130.7	125.4	114.5
2010	215.1	185.8	172.3	160.5	146.4	138.8	134.5	127.3	123.7	114.5
2011	215.8	186.5	174.6	157.8	145.8	139.7	131.2	127.7	122.2	111.8
2012	211.5	184.7	170.7	155.9	146.6	136.7	127.8	123.7	120.7	110.6

**Figure 3 - Estimated additional annual five-year survivors**

Linear projections - 2006-2010 incidence standardisation	Years of diagnosis					
	2006-2010	2007-2011	2008-2012	2009-2013	2010-2014	2011-2015
Total five-year survivors	598,044	610,325	623,027	635,448	647,940	660,431
Average annual 5-year survivors	119,609	122,065	124,605	127,090	129,588	132,086
Improvement vs baseline (five-year survivors)	0	2,456	4,997	7,481	9,979	12,477

Maximum range	Years of diagnosis					
	2006-2010	2007-2011	2008-2012	2009-2013	2010-2014	2011-2015
Total five-year survivors	562,487	603,187	615,321	627,139	639,036	650,933
Average annual 5-year survivors	112,497	120,637	123,064	125,428	127,807	130,187
Improvement vs baseline (five-year survivors)	0	8,140	10,567	12,930	15,310	17,689

Minimum range	Years of diagnosis					
	2006-2010	2007-2011	2008-2012	2009-2013	2010-2014	2011-2015
Total five-year survivors	591,527	574,391	587,180	599,379	611,725	624,072
Average annual 5-year survivors	118,305	114,878	117,436	119,876	122,345	124,814
Improvement vs baseline (five-year survivors)	0	-3,427	-869	1,570	4,040	6,509

**Figure 4 Number of diagnostic tests performed monthly from May 2010 to September 2014**

Month/year	Number of diagnostic tests performed
May 2010	1,187,490
June 2010	1,301,832
July 2010	1,299,484
August 2010	1,220,625
September 2010	1,287,434
October 2010	1,272,328
November 2010	1,321,547
December 2010	1,125,609
January 2011	1,240,157
February 2011	1,211,878
March 2011	1,389,085

<b>Month/year</b>	<b>Number of diagnostic tests performed</b>
April 2011	1,166,518
May 2011	1,284,065
June 2011	1,367,201
July 2011	1,318,878
August 2011	1,324,157
September 2011	1,342,239
October 2011	1,332,402
November 2011	1,394,495
December 2011	1,225,588
January 2012	1,370,595
February 2012	1,334,005
March 2012	1,414,209
April 2012	1,296,649
May 2012	1,489,239
June 2012	1,301,722
July 2012	1,450,847
August 2012	1,417,630
September 2012	1,349,835
October 2012	1,532,924
November 2012	1,491,399
December 2012	1,267,555
January 2013	1,487,229
February 2013	1,358,698
March 2013	1,403,030

<b>Month/year</b>	<b>Number of diagnostic tests performed</b>
April 2013	1,474,547
May 2013	1,486,035
June 2013	1,427,328
July 2013	1,559,851
August 2013	1,439,626
September 2013	1,458,794
October 2013	1,600,440
November 2013	1,525,711
December 2013	1,394,662
January 2014	1,595,250
February 2014	1,460,583
March 2014	1,557,219
April 2014	1,530,363
May 2014	1,543,591
June 2014	1,580,337
July 2014	1,643,857
August 2014	1,477,167
September 2014	1,606,556