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### **FOREWORD**

Cancer remains one of the biggest challenges facing the NHS in England. It is responsible for more than one in four deaths in the UK<sup>1</sup>; during 2011, one person died from cancer every four minutes<sup>2</sup>. With an ageing population, the number of people living with a cancer diagnosis is set to double from 2 million in 2010 to 4 million by 2030<sup>3</sup>. There is therefore an increasingly urgent need to tackle cancer.

Encouragingly, England's one-, five-, and ten-year cancer survival rates have improved significantly over the last forty years<sup>4</sup>. In the 1970s, 1 in 4 people survived their cancer for ten years; today that figure has doubled to 1 in 2<sup>5</sup>. This is certainly welcome progress – but there is much more to do. UK survival rates continue to lag behind comparable European countries, and, more importantly, this gap is not closing<sup>6</sup>.

The Cancer Campaigning Group's message is simple. Important progress has been made over the last 20 years since the publication of the landmark *Calman-Hine* report<sup>7</sup> – but cancer is not 'done'. We must protect and build upon successes to date to bring England's outcomes in line with the best in Europe.

Continuing to improve our survival rates will depend on meeting the highest standards of quality in six key areas: prevention and public health; screening; early diagnosis; treatments, services and commissioning; survivorship; and research. In this report, we set out our visions for the future of cancer for these six areas: long-term ambitions to deliver world-leading cancer outcomes. Government, the charity and voluntary sector, industry, the NHS, public health and social care systems, and the research and academic community must work collaboratively to achieve these goals. Fundamentally, strategic direction and leadership at the highest levels is essential to making these visions a reality.

The 60 members of the Cancer Campaigning Group urgently call on all political parties to recognise and reiterate that England's cancer journey is not yet complete. We want all political parties to continue to name cancer as a priority for the NHS, committing to strive for the best ahead of the 2015 General Election and beyond. We have set out three urgent recommendations for the next Government and NHS leaders to deliver during the 2015-2020 Parliament; actions which will improve experiences of treatment and care, improve quality of life for cancer survivors and save more lives – ultimately, bringing our cancer outcomes in line with the best in Europe.

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### **EXECUTIVE SUMMARY**

The 60 members of the Cancer Campaigning Group have an ambition for the Government, the charity and voluntary sector, industry, the NHS, public health and social care systems, and the research and academic community to deliver truly world-class cancer outcomes. We should be among the best in Europe.

England's one-, five-, and ten-year cancer survival rates have improved significantly over the last forty years<sup>8</sup>. In the 1970s, 1 in 4 people survived their cancer for ten years; today that figure has doubled to 1 in 2<sup>9</sup>. However, our survival rates continue to lag behind comparable European countries and, more importantly, this gap is not closing<sup>10</sup>.

Continuing to improve our survival rates will depend on meeting the highest standards of quality in six key areas: prevention and public health; screening; early diagnosis; treatments, services and commissioning; survivorship; and research. In this report, we set out our visions for the future of cancer for these six areas: long-term ambitions to deliver world-leading cancer outcomes.

The Cancer Campaigning Group strongly supports a joined-up approach between the Government, NHS England, Public Health England, clinical commissioning groups (CCGs), local authorities, strategic clinical networks and all relevant stakeholders to drive and implement high quality national strategic direction and evidence-based policy change.

### OUR VISION FOR THE FUTURE OF PREVENTION AND PUBLIC HEALTH

It is estimated that over 40% of cancers could be prevented by changes to lifestyle and environment<sup>11</sup>. The Cancer Campaigning Group would like to see the NHS and public health systems working closely together to provide strong national and local frameworks for preventing more cancers. Prevention programmes should include evidence-based public health campaigns to raise awareness of the risk factors associated with cancer, national and local tobacco control plans, legislation (for example on tobacco and alcohol) where appropriate, and better training and support for health professionals. The public should be supported in taking action to live healthier lives.

#### OUR VISION FOR THE FUTURE OF SCREENING

Screening programmes can play an important role in improving survival rates through early diagnosis. In some cases, they can also prevent cancers. The Cancer Campaigning Group wants to see current programmes protected, or enhanced where appropriate, over the next decade, as well as initiatives to promote take-up of screening invitations. We support the introduction of new screening programmes – particularly for cancers not covered by existing programmes – once robust evidence demonstrating both clinical and cost effectiveness is provided.

### OUR VISION FOR THE FUTURE OF AWARENESS AND EARLY DIAGNOSIS

Early diagnosis represents one of the biggest opportunities to improve cancer outcomes. We are calling on political leaders to reiterate their support for national leadership on early diagnosis, including the Public Awareness campaigns run through the National Awareness and Early Diagnosis Initiative. The NHS and public health systems must work effectively to help people to recognise the symptoms and signs of cancer and encourage them to seek advice from their GP or other healthcare professional as soon as possible. Timely access to diagnostic tests where cancer is suspected is essential and GPs must be given more support to recognise cancer symptoms and refer people appropriately for further investigations.

### OUR VISION FOR THE FUTURE OF TREATMENTS, SERVICES AND COMMISSIONING

People with cancer should be able to access the full range of clinically appropriate and evidence-based treatments and services. While national commissioning for some specialised cancer services should be protected, the Cancer Campaigning Group hopes that commissioning decisions will be brought closer to the patient, with personalised care plans having an important role to play. The provision of clear and age-appropriate information and advice can support high quality decision-making and treatment, and is essential to ensuring patients can access the best services. This requires national, regional and local leadership in cancer services to be adequately resourced and supported.

#### OUR VISION FOR THE FUTURE OF SURVIVORSHIP

With England's cancer survival rates on a welcome increase, far more should be done to support the growing number of people living beyond cancer to improve their quality of life. The Cancer Campaigning Group hopes that every cancer patient will be offered the Recovery Package which includes a holistic needs assessment and written care plan to ensure that their full range of needs are met.

#### OUR VISION FOR THE FUTURE OF RESEARCH

The UK should rightly be proud of our position as a world-leader in scientific research and medical innovation, and the contribution of charities, industry, Government, academic institutions and the NHS are vital to maintaining this position. Sustained investment in research – including maintaining the Government's science budget - as well as the appropriate infrastructure and opportunities for effective collaboration are vital to driving leading research. The UK should maintain and build on its leading recruitment rates to clinical trials, with further efforts made to reduce the administration requirements surrounding clinical trials and proper funding provided nationally to ensure effective patient involvement. Ultimately, the UK's world-leading science base must translate research into significant clinical outcomes which benefit patients as soon as possible.

# THE CANCER CAMPAIGNING GROUP URGENTLY CALLS ON ALL POLITICAL PARTIES TO CONTINUE TO NAME CANCER AS A PRIORITY FOR THE NHS, COMMITTING TO STRIVE FOR THE BEST AHEAD OF THE 2015 ELECTION AND BEYOND.

We have set out recommendations for the next Government and NHS leaders to deliver during the 2015-2020 Parliament; actions which will improve experiences of treatment and care, improve quality of life for cancer survivors and save more lives — ultimately, bringing England's cancer outcomes in line with the best in Europe.

#### STRATEGIC PLAN AND ANNUAL UPDATE

The next Government should work with NHS England and Public Health England to introduce a five-year strategic plan for improving cancer outcomes so that they are among the best in Europe. This must outline the long-term ambitions for cancer across the patient pathway, including benchmarks for success, and set out how the NHS, public health and social care systems will be supported, resourced, enabled and held accountable for achieving the best outcomes in Europe. The plan must be accompanied by an annual implementation update, assessing the progress made in the previous year and next steps to deliver the plan.

#### $\mathsf{DATA}$

The NHS must continue to improve the scope and scale of data collection, using data to drive further research into personalised services and underpin more informed commissioning that is responsive to patient need and innovation. This will underpin the development and delivery of evidence-based interventions and services, while measuring impact more effectively. A framework for maintaining and improving our data capabilities must be included within the five-year strategic plan.

#### INTEGRATED CANCER SERVICES

Commissioners and providers must be supported to design and deliver integrated cancer services that are coordinated and seamlessly built around the needs of a patient. Improving patient experience must be central to this. The national strategic plan should outline the responsibilities for integrated cancer services, including the role that regional and local organisations can play.

### INTRODUCTION

'Cancer' is a collection of over 200 diseases<sup>12</sup> which may have a devastating impact on an individual, their family and carers. Incidence has been increasing over the past 40 years<sup>13</sup> and projections suggest that the number of people living with a cancer diagnosis in the UK is set to double from more than 2 million in 2010 to 4 million by 2030<sup>14</sup>.

### POORER OUTCOMES THAN COMPARABLE EUROPEAN COUNTRIES

While incidence rates have been rising, mortality rates have been decreasing<sup>15</sup>. However, cancer still remains responsible for more than one in four deaths in the UK<sup>16</sup>.

It is perhaps unsurprising then, that cancer has been named the number one public health concern by members of the public. In a recent Public Health England survey, over a third of people questioned (34 per cent, n=1625) named cancer, unprompted, as their biggest concern – ahead of dementia (23 per cent) and drug abuse, smoking and obesity (each at 19 per cent)<sup>17</sup>.

Together with experiences of treatment and services, quality of life for survivors and mortality rates, cancer survival rates are a key measure of the effectiveness – and outcomes – of cancer services. England's one-, five- and ten- year cancer survival rates have been increasing over recent years<sup>18</sup>. This is welcome progress and may be attributed to a range of factors, including earlier diagnosis, more detailed research and improved treatments and services<sup>19</sup>.

However, studies including the EUROCARE series<sup>20</sup> and the International Cancer Benchmarking Partnership (ICBP)<sup>21</sup>, have shown that, despite improving survival rates, we continue to lag behind comparable European countries – and, moreover, that this gap, between the UK and the best – or even average – in Europe, is not closing.

### TWO DECADES OF NATIONAL INITIATIVES TO IMPROVE CANCER SERVICES

The Calman-Hine report, published in 1995, was the first comprehensive report assessing cancer services in the UK<sup>22</sup>. It put in motion a period of national investment and reform of cancer services across England. These were designed to improve the quality of cancer services and bring our outcomes into line with the best of Europe. There have since been three major publications seeking to drive, at a national level, continued progress throughout the NHS: *The NHS Cancer Plan*<sup>23</sup> in 2000, the *Cancer Reform Strategy*<sup>24</sup> in 2007, and *Improving Outcomes: A strategy for cancer*<sup>25</sup> in 2011.

Much of the success to date in improving England's cancer outcomes has been coordinated and driven by these national strategies, supported by national, regional and local expertise, innovation and leadership. Since 2000, cancer services received significant dedicated resource, supported by a national infrastructure and leadership team to drive forward improvements in cancer. Until 2013, this included: a National Cancer Action Team (now disbanded) to coordinate improvements centrally; a National Clinical Director (now reporting to NHS England rather than the Secretary of State) to provide expert insight and leadership; and dedicated local cancer networks (now disbanded) to support providers and commissioners to improve the design and delivery of local services through local insight and expertise<sup>26</sup>. Being seen as a national and clinical priority helped cancer to receive sustained commitment throughout the NHS to improve outcomes and experience - the impact of which is illustrated through our improving mortality and survival rates.

#### TRAILING MOMENTUM: CANCER IS NOT 'DONE'

In recent years and months, however, there has been increasing concern amongst the cancer community that cancer could be perceived as 'done' at the highest level.

The Cancer Campaigning Group has already expressed concern that some of the national initiatives which have been successful in driving improvements nationally throughout the NHS have been diluted over recent years in both resource and focus. Most notably, the cancer networks are now part of generic Strategic Clinical Networks, meaning the number of specialist cancer commissioners and the financial support available to them has declined; and the National Cancer Action Team has been subsumed into a larger organisation without a specific focus on cancer. The Cancer Campaigning Group believes that these changes risk not only a loss of expertise and national leadership but, ultimately, a loss of momentum.

Commitments in *Improving Outcomes: A strategy for cancer* have sought to maintain and build upon progress, including by improving data accessibility and establishing a clear benchmark for success, by saving an additional 5,000 lives by 2015 to bring our survival rates in line with the European average<sup>27</sup>. Funding has also increased in real terms by 21 per cent between 2006-07 and 2012-13<sup>28</sup>. However, with our survival rates still lagging behind comparable European countries, patients, their families and carers will bear the impact if the focus slips.

Given our increasingly ageing population in which individuals often have complex co-morbidities, it is more important than ever that we maintain progress and momentum. This will not only improve patients' outcomes and experience of care, it can also help the NHS reduce incidences of unplanned and emergency costs associated with late diagnosis and escalated health and care needs.

#### AIMS OF THIS REPORT

As we come closer to the 20<sup>th</sup> year since the *Calman-Hine* report was published, the Cancer Campaigning Group feels that the time is right to reflect on the progress made since its publication.

This report:

- Assesses progress that has been made over the last 20 years across the NHS in six key areas, focusing on headline policy initiatives which have driven improvements in cancer outcomes:
  - prevention and public health
  - screening
  - early diagnosis
  - treatments, services and commissioning
  - survivorship
  - research
- Sets out the Cancer Campaigning Group's vision for how to protect and build upon this progress, to bring our outcomes in line with the best in Europe
- Calls on all political parties to make cancer a priority ahead of the 2015 General Election and beyond
- Concludes with three urgent recommendations for the next Government and NHS leaders to deliver during the 2015-2020 Parliament

Ultimately, this report highlights that, while much progress has been made to date in improving England's cancer outcomes, much more needs to be done to ensure that England's survival rates continue to improve and meet the best in Europe. National political and NHS leadership is essential to providing strategic direction and enabling this change. The Group looks forward to working collaboratively to make this a reality.

### CANCER IN CONTEXT: INCIDENCE, MORTALITY AND SURVIVAL

#### CANCER INCIDENCE: A GROWING CHALLENGE

As figure one illustrates, the number of people receiving a cancer diagnosis has been increasing over the last forty years. Age standardised rates per 100,000 persons have risen from 292 in 1976 to 396 in 2011<sup>29</sup>.

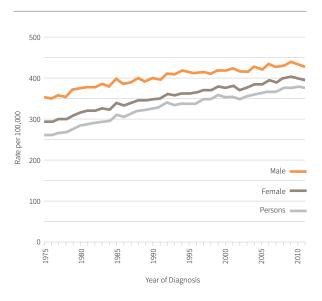


Figure 1: Age-standardised incidence rates per 100,000 population, by sex, UK, 2011<sup>30</sup>

Projections suggest that the number of people living with a cancer diagnosis in the UK is set to **double** from more than **2 million in 2010 to 4 million by 2030**<sup>31</sup>.

Cancer incidence rates are highest in older people, with over **60 per cent of new cases diagnosed each year in the UK in people aged 65 and over**<sup>32</sup>. With an ageing population, addressing cancer effectively is becoming an increasingly urgent challenge.

### CANCER MORTALITY: DECREASING BUT STILL SIGNIFICANT

While incidence rates have been rising, figure 2 illustrates that mortality rates have been decreasing. This may be attributed to a number of reasons, including, in part, earlier diagnosis, more effective treatment and improved research.

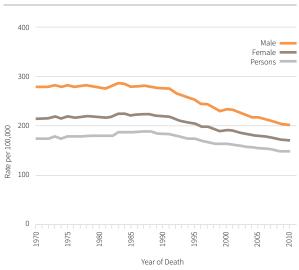


Figure 2: Age-standardised mortality rates, UK, 1971-2011<sup>33</sup>

However, while mortality trends have been decreasing, cancer still remains responsible for **more than one in** four deaths in the UK<sup>34</sup>.

### CANCER SURVIVAL: LAGGING BEHIND COMPARABLE EUROPEAN COUNTRIES

One-, five- and ten- year survival have both improved in the past decade<sup>35</sup>. This is welcome progress and may be attributed to a number of factors, including earlier diagnosis, better treatment and care.

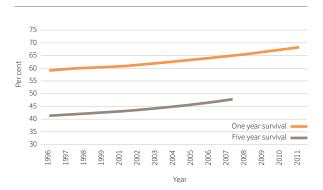


Figure 3: One- and five-year survival for all cancers combined, England <sup>36</sup>

However, while England's survival rates have been improving, they continue to lag behind comparable countries and this gap does not appear to be narrowing:

- The EUROCARE 5 study, published in 2014, showed that survival for many cancers is lower in the UK than Sweden, Norway and Finland<sup>37</sup>
- The International Cancer Benchmarking Partnership (ICBP) has highlighted that survival for breast, colorectal, lung and ovarian cancers are persistently lower in UK nations than Australia, Canada, Sweden and Norway<sup>38</sup>
- The ICBP also demonstrates that survival is particularly poor in the first year after diagnosis and among patients aged 65 and older<sup>39</sup>

Reasons for these gaps are varied and are explored later in this report, though they may include delayed diagnosis, underuse of successful treatments, unequal access to treatment (particularly among elderly people)<sup>40</sup> and a lack of support following treatment.

While significant progress has been made in recent years to address these issues, our comparatively poor survival rates underline the absolute imperative for continued and sustained efforts to improve cancer services across the entire pathway. This will require a collaborative approach between the Government, NHS England, Public Health England, clinical commissioning groups (CCGs), local authorities, strategic clinical networks and all relevant stakeholders to drive and implement high quality national strategic direction and evidence-based policy change. Leadership at the highest levels is essential to make this a reality and underpins our urgent recommendation for the next Government, NHS England and Public Health England to develop a five year strategic plan for 2015-20, setting out a national framework for continued improvements.

Systemic change to the national cancer framework can and should retain excellent practice from previous structures and policy interventions.

As we begin to understand the impact of the 2012 Health and Social Care Act, it is important to view cancer services in context. The next page sets out significant elements of the national framework for delivering better cancer outcomes since the seminal Calman-Hine Report of 1995.

The following six chapters trace the specific developments that have driven improvements across the patient pathway, reviewing the impact they have had to date. For each part of the pathway, the Cancer Campaigning Group has set out its vision for cancer over the coming years to protect and build on progress to date and, ultimately, improve our outcomes in line with the best in Europe.

# A TIMELINE OF CANCER POLICIES: ADDRESSING THE CANCER CHALLENGE

1995 2000 2001 2005 2006 2007 *IMPROVING* SMOKEFREE LEGISLATION A POLICY NHS CANCER EXPERIMENTAL FRAMEWORK FOR **OUTCOMES IN** CANCER PLAN CANCER INTRODUCED COMMISSIONING PUBLISHED, RESEARCH CHILDREN AND MEDICINE YOUNG PEOPLE IN ENGLAND CANCER INCLUDING SERVICES WITH CANCER **ESTABLISHED** LAUNCHED (CALMAN-PUBLISHED HINE REPORT) WAITING TIME CANCER PUBLISHED REFORM STRATEGY **PUBLISHED** 

62 DAY

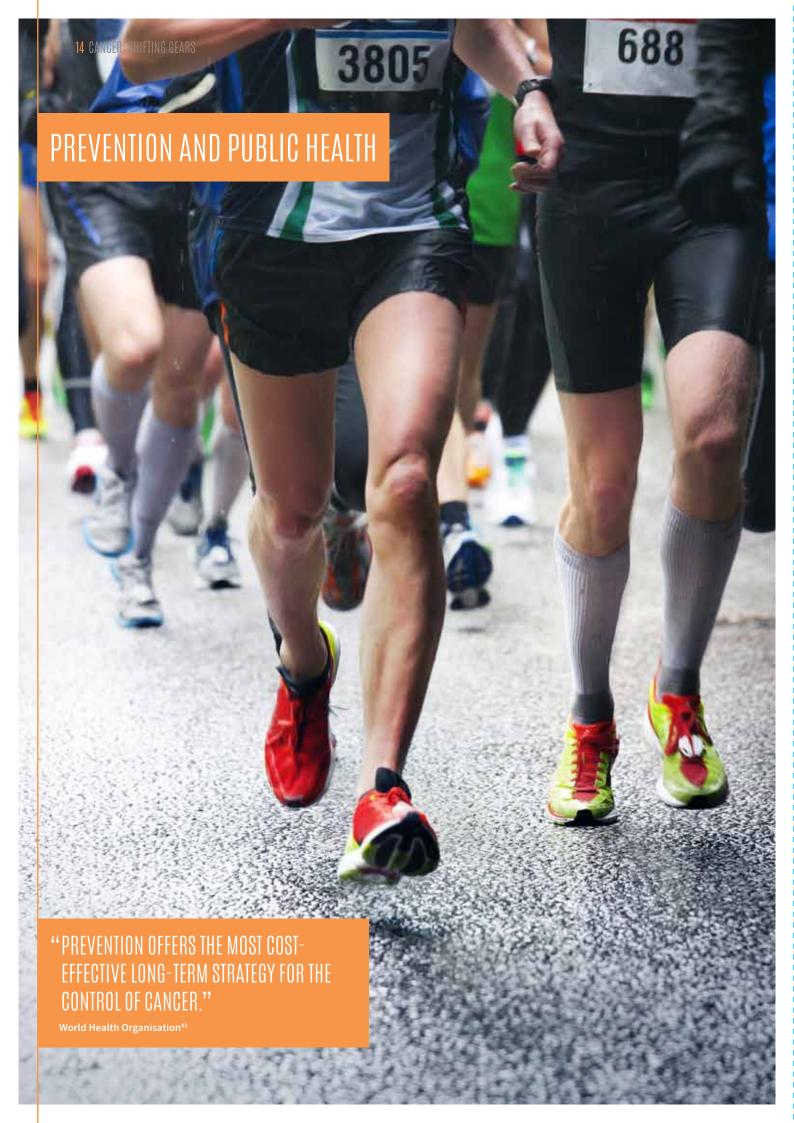
AND 31 DAY WAITING TIME

INTRODUCED

Figure 4: A timeline of major national initiatives that have been introduced to support the NHS to improve cancer outcomes and patient care

2010 2011 2012 2013 2008 2009 CANCER DRUGS FUND FIRST 'BE CLEAR ON NATIONAL RADIOTHERAPY HEALTH AND SOCIAL CARE CANCER PRESCRIPTIONS INNOVATION **ESTABLISHED** FOR PEOPLE ACT 2012 NETWORK IMPLEMENTED LAUNCHED BY CANCER CAMPAIGN INTRODUCED GENOMICS **IMPROVING** CANCER **EXPERIENCE** A STRATEGY SURVIVORSHIP INITIATIVE SURVEY FOR CANCER LAUNCHED PUBLISHED RESEARCH AND EARLY DIAGNOSIS <u>ESTABLISHED</u>

ESTABLISHED



### PREVENTION AND PUBLIC HEALTH

Over 40 per cent of cancers diagnosed each year in the UK are linked to a combination of 14 major lifestyle and environmental factors<sup>44</sup> – all of which (with the exception of ionising radiation) are potentially avoidable<sup>45</sup>. Preventative measures therefore have a major role to play in reducing future cancer incidence and therefore mortality.

42 per cent of cancers could be prevented by changes to lifestyle and environment<sup>41</sup>. That's more than 135,000 people every year who would never have to face the devastating reality of a cancer diagnosis<sup>42</sup>.

Successive governments have introduced initiatives to raise awareness of the preventable causes of cancer and to support behavioural change to help people reduce their risk. These have gone some way to help save lives and alleviate avoidable pressures on the NHS – but there is still a long way to go, and government initiatives and campaigns need to be combined with education about the risk factors and signs of cancer in order to bring about significant change.

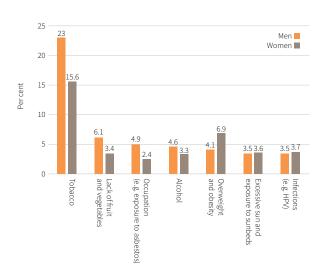


Figure 5: Percentage of incident cancer cases in the UK in 2010 due to a selection of lifestyle and environmental factors<sup>46</sup>

#### SMOKING-RELATED CANCER

Smoking is the primary cause of preventable morbidity and premature death, accounting for 81,400 adult deaths in England in 2009<sup>48</sup>. In England, deaths from smoking are more numerous than the next six most common causes of preventable death combined (drug use, road accidents, other accidents and falls, preventable diabetes, suicide and alcohol abuse)<sup>49</sup>.

Tobacco is responsible for more avoidable cases of cancer than any other risk factor<sup>47</sup>.

Tobacco is responsible for more avoidable cases of cancer than any other risk factor. In 2010 approximately one fifth (19.4 per cent) – or around 60,000 cases – of cancers in the UK<sup>50</sup> were linked to tobacco use. More than one in four cancer deaths are caused by tobacco<sup>51</sup>.

Despite significant falls in smoking rates between 1950 and 1990, smoking rates remained stable throughout the 1990s and actually rose among children aged 15 (from 25 per cent in 1990 to 28 per cent in 1994), before falling again<sup>52</sup>.

Nonetheless, a series of Government measures, as outlined overleaf, have helped to contribute to falling smoking rates since 2000, with rates falling from 27 per cent to below 20 per cent for the first time in 80 years<sup>53</sup>. While it takes many years to assess the impact of tobacco control initiatives on smoking uptake, evidence suggests these measures have had a significant effect. However, with tobacco still the single most important cause of preventable death in the UK<sup>54</sup>, much more needs to be done.

### Summary of tobacco control measures introduced since 2000

2000 - Stop smoking services introduced

2001 - Nicotine Replacement Therapies made available

2003 - Tobacco advertising and marketing regulations tightened

2003 - Graphic health warnings on packs introduced

2003 - WHO Framework Convention on Tobacco Control adopted

2007 - Ban on smoking in public places introduced

2012 - Point of sale displays banned in large shops

Figure 6: Smoking rates in men, women and all persons aged 16 and over, 1998-2012 (per cent)<sup>55</sup>

The Cancer Campaigning Group is calling for the swift introduction of standardised tobacco packaging in the UK, with Regulations being passed before the General Election. In addition, in line with the commitments laid out in Healthy lives, Healthy people: A Tobacco Control Plan for England<sup>56</sup>, the Cancer Campaigning Group also calls on the Government to implement the tobacco display ban in all retailers by April 2015; to continue to invest in mass media campaigns to encourage cessation; to ensure support is in place for local authorities who are responsible for Stop Smoking Services; and to introduce a tobacco tax escalator of 5 per cent above inflation. Together, these measures can help ensure that England goes much further to support people who want to quit and prevent young people from starting an addiction which kills one in two long-term users<sup>57</sup>.

#### DIET-RELATED CANCER

9.2% of cancers – more than 29,000 cases a year – have been found to be linked to dietary factors: these include deficient intake of fruit and vegetables, consumption of red and processed meat, deficient intake of fibre, and excess consumption of salt<sup>59</sup>.

Diet-related cancers are the second most common type of preventable cancer after smoking<sup>58</sup>.

The introduction of colour coded food labelling in 2013 was a welcome step in helping people to make informed decisions about their food. The Cancer Campaigning Group supports more research to understand policy interventions that could help us make more progress.

### OBESITY-RELATED CANCER AND THE IMPORTANCE OF PHYSICAL EXERCISE

Being overweight is associated with an increased risk of developing cancer. 5.5% of all cancers – around 18,200 cases– in 2010 were linked to obesity or being overweight, mostly affecting those with large bowel or breast cancer<sup>60</sup>.

Obesity among 2-10 year olds rose from 10 per cent in 1995 to around 13 per cent in 2010-201261.

The number of obese or overweight people has increased steadily in the UK since 1993<sup>62</sup>. This is a growing problem in children, with obesity among 2-10 year olds rising from 10 per cent in 1995 to around 13 per cent in 2010-2012<sup>63</sup>. Change4Life, introduced by the Government in 2009, has sought to address this problem, by investing in school sports clubs, encouraging activities such as walking to school, and focusing on healthier eating.

Separately, but linked to obesity, too little physical activity has been estimated to contribute to one per cent of cancer cases in the UK each year, particularly to uterine, breast and colon cancers<sup>64</sup>. In the UK, adults are advised to do at least 2.5 hours of moderate intensity physical activity a week. Evidence suggests that being physically active during and after cancer can:

- Improve physical and psychological well-being
- Improve overall survival rates and reduce the risk of recurrence
- Reduce the risk of co-morbidities

Future governments, Public Health England and local authorities should continue to work together to encourage healthier diets and promote physical activity through evidence-based interventions. Public Health England should explore ways to continue to raise public awareness of obesity and being overweight as a major risk factor for cancer. Local authorities must ensure that their health and wellbeing strategies have appropriate plans in place to improve levels of physical exercise and encourage healthier eating.

#### ALCOHOL-RELATED CANCER

4% of cancers in the UK can be attributed to alcohol consumption<sup>66</sup>. Despite this, awareness of alcohol consumption as a risk factor for cancer is still relatively low<sup>67</sup>.

While there does appear to have been some reduction in both the quantity of alcohol consumed, and the regularity with which alcohol is consumed to excess since 2005<sup>68</sup>, the prevalence of cancers related to alcohol consumption in the UK remains a concern.

Minimum unit pricing is evidence-based and it has been shown internationally that it can reduce alcohol-related deaths<sup>69</sup>. The Government should seek to introduce legislation to enforce the minimum pricing of alcohol as soon as possible.

Further, Public Health England must continue to raise awareness of the importance of alcohol as a risk factor for cancer, and support local authorities to ensure that their local health and wellbeing strategies have adequate plans in place to reduce harmful levels of alcohol consumption.

#### UV RADIATION-RELATED CANCER

There has been a fivefold increase in skin cancer incidence since 1975. Around 13,300 cases of malignant melanoma were diagnosed in 2011 in the UK<sup>71</sup>. Like most cancers, skin cancer is more common with increasing age, but malignant melanoma rates are disproportionately high in younger people. Between 2009 and 2011, over a quarter of cases were diagnosed in people aged under 50<sup>72</sup>.

14 per cent of men, and nine per cent of women drank alcohol on five or more days in the week in 2012<sup>65</sup>.

Much of this increase has been attributed to the rise in the use of sunbeds, as well as the increasing numbers of holidays abroad without adequate protection from the sun<sup>73</sup>. In order to counteract this trend, Public Health England must lead the way, in partnership with local authorities, in increasing public awareness of the causes of skin cancer through public campaigns. In addition, the Cancer Campaigning Group encourages clinicians to continue to use the skin cancer toolkit which has been developed by Cancer Research UK and the British Association of Dermatologists<sup>74</sup>.

Malignant melanoma incidence rates have increased more rapidly since the mid-1970s than any of the current ten most common cancers in males and females<sup>70</sup>.

#### INFECTIONS

Human Papillomavirus (HPV) vaccination protects against two types of HPV virus which together are responsible for about 70% of cervical cancers<sup>75</sup>. Research indicates that the HPV vaccine, which has been offered to all girls aged 12 and 13 since 2008, provides effective vaccination for at least 20 years<sup>76</sup>.

It is of some concern that there is significant geographical variation in HPV vaccination uptake, as demonstrated in Figure 7 below. Clinical commissioning groups must ensure that HPV vaccination is consistently offered, and variations in uptake are understood and tackled within their area. This could include local awareness initiatives if low uptake is linked to a specific group, such as those with certain religious or cultural concerns.

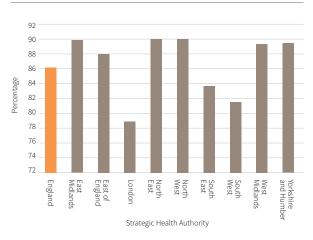
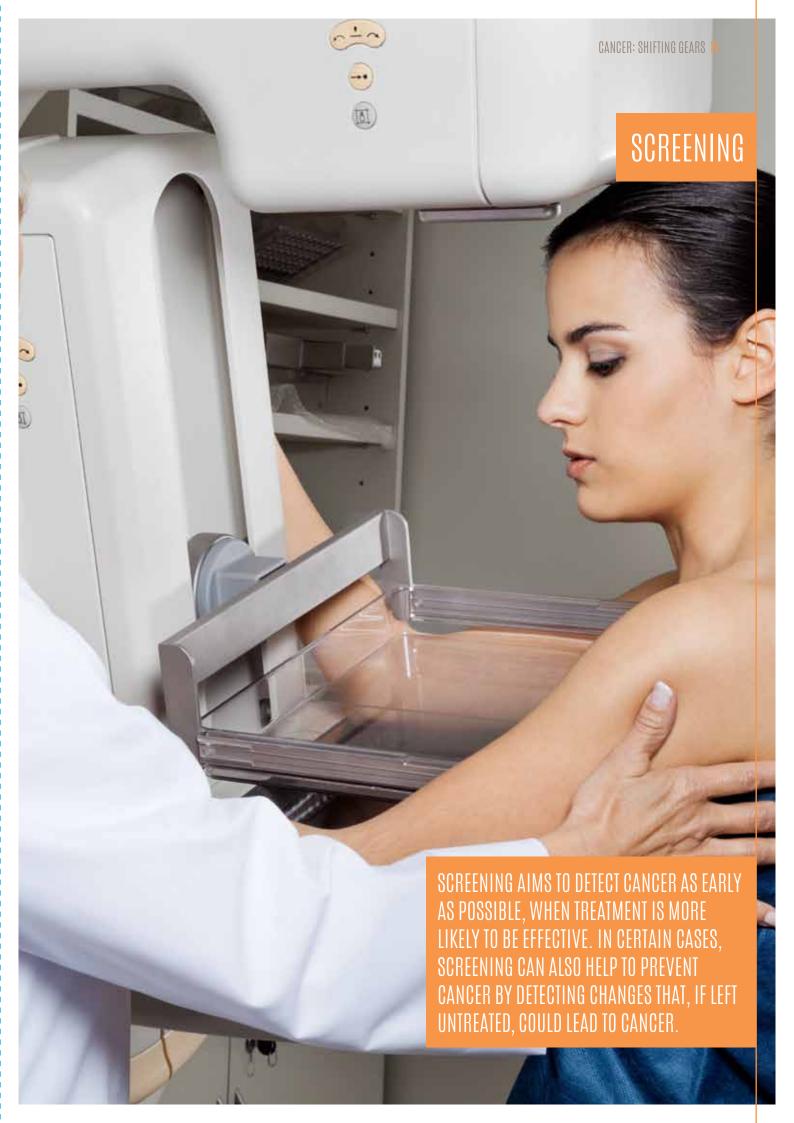


Figure 7: HPV vaccination coverage (2012-2013, per cent) by Strategic Health Authority<sup>77</sup>

#### OUR VISION FOR THE FUTURE OF PREVENTION AND PUBLIC HEALTH

It is estimated that over 40% of cancers could be prevented by changes to lifestyle and environment<sup>78</sup>. The Cancer Campaigning Group would like to see the NHS and public health systems working closely together to provide strong national and local frameworks for preventing more cancers. Prevention programmes should include evidence-based public health campaigns to raise awareness of the risk factors associated with cancer, national and local tobacco control plans, legislation (for example on tobacco and alcohol) where appropriate, and better training and support for health professionals. The public should be supported in taking action to live healthier lives.



### **SCREENING**

Cancer screening programmes look for early signs of cancer in otherwise healthy, symptomless people. Screening aims to detect cancer as early as possible, when treatment is more likely to be effective. In certain cases, screening can also help to prevent cancer by detecting changes that, if left untreated, could lead to cancer.

The NHS currently screens for breast, cervical and bowel cancer. These national screening programmes are coordinated by the national office of the NHS Cancer Screening Programmes, part of Public Health England. The scope of these evidence-based screening programmes has increased over the past decade, and their impact is beginning to show.

Current screening programmes must continue to be fully resourced — including through investment in improved screening technologies — and extended where appropriate when evidence demonstrates benefit. Ongoing research into diagnostic tests and screening programmes for other cancers such as ovarian, lung and prostate is also essential, and, if proven to be clinically and cost effective, these programmes should be rolled out quickly to ensure people can benefit<sup>79</sup>.

The NHS Cervical Screening Programme screens more than 3 million women each year and prevents up to 75 per cent of cervical cancers.

The NHS Cervical Screening Programme detects pre-cancerous cell changes in a cervix by reviewing samples under a microscope (cytology). When abnormal cells are found, treatment can be initiated to remove or destroy these cells before they develop into invasive cancer. The Programme screens more than 3 million women each year and prevents up to 75 per cent of cervical cancers<sup>81</sup>.

The NHS Cancer Screening Programme ran a project in 2008 to examine how to introduce testing for HPV as part of the Cervical Screening Programme <sup>82</sup>. Following a successful evaluation, this has been introduced into the Programme and involves testing cervical samples where borderline or low-grade cell changes are found, for HPV. If samples are found to be HPV positive then further investigation is initiated to see if any treatment is needed. In addition, the NHS is currently piloting HPV primary screening<sup>83</sup>. This involves testing cervical samples for HPV before analysing them for the presence of abnormal cells. The benefits of this approach are being tested and, if proven effective, primary screening for HPV should be rolled out nationwide quickly and consistently.

Since 2006, the NHS Bowel Cancer Screening Programme has managed over 95,000 patients for polyps and detected over 17,500 cancers<sup>84</sup>.

The NHS Breast Screening Programme diagnoses around a third of breast cancers and is estimated to save around 1,300 lives a year<sup>88</sup>.

#### The NHS Bowel Cancer Screening Programme

began in 2006. Offered to men and women between 60 and 75 years old, stool samples are tested for the presence of blood using a home-testing Faecal Occult Blood (FOB) kit. Further investigation of abnormal results aims to detect bowel cancer at an early stage or to detect polyps, which may develop into cancers over time. More than 12 million home testing kits have been returned to laboratories, over 95,000 patients have been managed for polyps and over 17,500 cancers have been detected.85

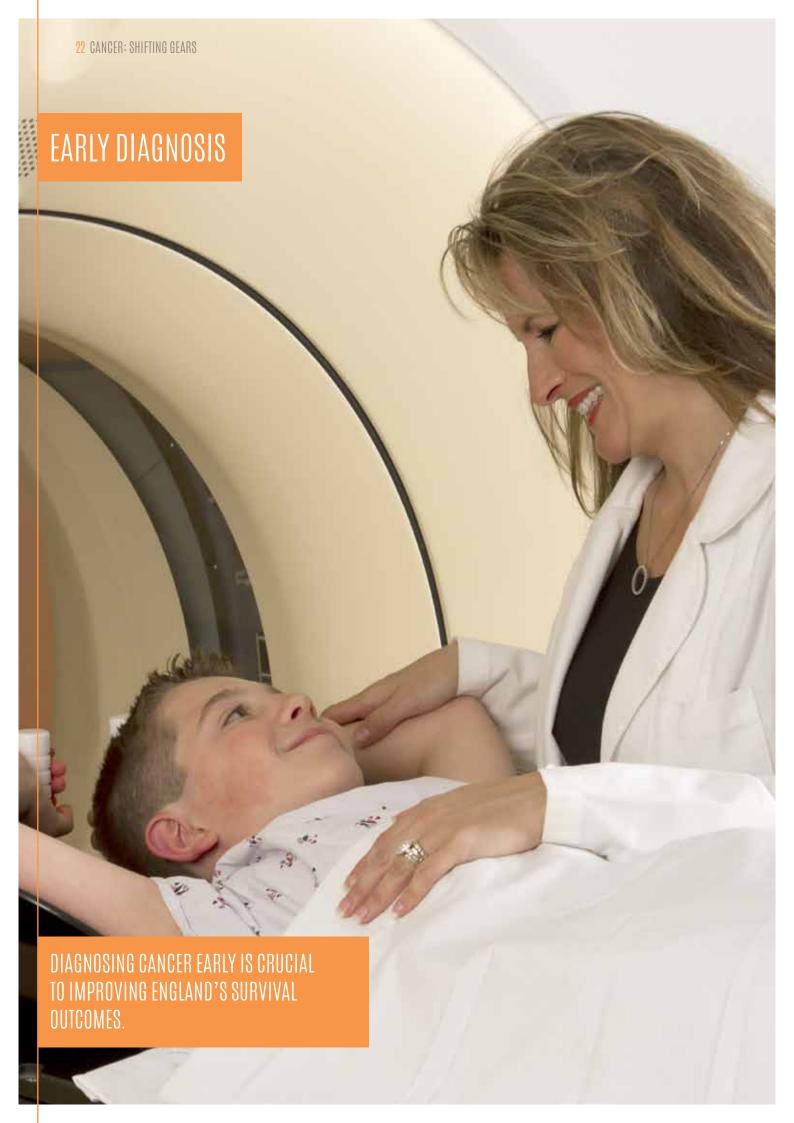
In 2010, the results of a 16 year trial of bowel scope screening using flexible sigmoidoscopy were published, showing conclusively that a one-off screen using flexible sigmoidoscopy could prevent up to a third of bowel cancers and reduce mortality by 43% in those screened<sup>86</sup>. The Government acted quickly to roll out the scheme, announcing pilots in 2012 and a schedule for full rollout of the test by 2016. The programme, now called 'Bowel Scope' could save thousands of lives a year once fully rolled out<sup>87</sup>, and is a great example of the impact screening programmes can have. It is essential that the service is given the funding and support it needs to implement Bowel Scope Screening to make sure the public can benefit as soon as possible.

The NHS Breast Screening Programme aims to detect breast cancer at an early stage. Women between the ages of 50 and 70 are invited every three years for an x-ray (mammogram), which detects small changes in breast tissue which may indicate cancers too small to be felt by the woman herself or a doctor. A randomised control trial evaluating the net effects of extending the age range for breast screening is now underway. Full roll-out of screening to women aged 47-49 and 71-73 is expected to be completed after 2016. The programme currently screens around 1.6 million women a year<sup>89</sup> and is estimated to save

around 1,300 lives a year<sup>90</sup>.

#### OUR VISION FOR THE FUTURE OF SCREENING

Screening programmes can play an important role in improving survival rates through early diagnosis. In some cases, they can also prevent cancers. The Cancer Campaigning Group wants to see current programmes protected, or enhanced where appropriate, over the next decade, as well as initiatives to promote take-up of screening invitations. We support the introduction of new screening programmes – particularly for cancers not covered by existing programmes – once robust evidence demonstrating both clinical and cost effectiveness is provided.



### EARLY DIAGNOSIS

Diagnosing cancer early is crucial to improving England's survival rates. In 2000, The *NHS Cancer Plan* set out measures to encourage early diagnosis by raising public awareness about the signs and symptoms of cancer, and extending NHS cancer screening programmes<sup>92</sup>. *Improving Outcomes: A Strategy for Cancer* set the ambition of saving an additional 5,000 lives per year by 2014/15, and recognised that "it is mainly through earlier diagnosis where these lives will be saved"<sup>93</sup>.

"We have only really gone halfway along the path to making our survival comparable to the best in Europe. Now is the time to grab the opportunity to at long last deliver earlier diagnosis, earlier stage of diagnosis, and therefore improve our survival."

Sean Duffy, National Clinical Director for Cancer<sup>91</sup>

#### EVIDENCE OF DELAYED DETECTION AND DIAGNOSIS

There are a number of data sources that provide evidence of delays in diagnosis across the NHS in England:

- One year survival rates
- Emergency presentation and diagnosis rates
- Variation in urgent referral waiting times
   (2 week waits)

#### One-year survival rates

One-year survival figures can demonstrate the impact and extent of delayed diagnosis. Better one-year survival figures suggest that cancers are being diagnosed earlier and treatment begins sooner, improving the chance of a positive outcome95. This was most recently highlighted in a report published by Public Health England during August 2014. Examining one-year survival for patients diagnosed with breast, lung, prostate, colorectal and ovarian cancer in 2012, the report found that "survival is always poorer in cancers diagnosed at a later stage", a pattern consistent across both sexes, all age groups and all deprivation quintiles<sup>96</sup>. Survival rates at five- and ten-years are also influenced by earlier detection and diagnosis, but are also strongly dependent on additional factors including the success of treatment97.

#### CAUSES OF DELAYED DIAGNOSIS94

#### Patient delay

- People may not recognise the signs and symptoms of cancer
- People may recognise the signs and symptoms of cancer but delay making a GP appointment through fear of diagnosis
- People may not take up invitations to screening

#### **Doctor delay**

- GPs may not recognise potential cancer-related symptoms
- GPs may delay investigating symptoms or referring the patient on for specialist assessment

#### System delay

- Unnecessary waits for investigation or assessment, such as delays in securing first GP appointment or hospital visit to see a specialist, and variations in access to the latest diagnostic tests
- Unnecessary waits between the decision to treat and the time that treatment starts

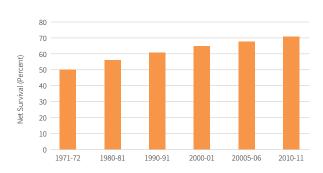


Figure 8: Age-standardised one-year net survival, England and Wales, 1971-2011 (All cancers excluding non-melanoma skin cancer)<sup>99</sup>

Encouragingly, one-year survival figures have improved over time. However, as set out earlier in this report, survival rates in England are still persistently lower than comparable European countries<sup>98</sup>. Poorer survival may be attributed to a number of factors, but late diagnosis must be addressed as a priority to improve our survival rates.

#### Routes to diagnosis: Emergency presentation

Another proxy measure for early diagnosis is where and how a cancer diagnosis takes place. Emergency presentation can be via A&E but also includes emergency GP referral, emergency consultant outpatient referral, emergency transfer, or an emergency admission or attendance.

### Between 2006 and 2010, 23 per cent of cancers were diagnosed through emergency presentation.

Figures from the National Cancer Intelligence Network (NCIN) show that between 2006 and 2010, 23 per cent of cancers were diagnosed through emergency presentation<sup>101</sup>. Emergency diagnosis is particularly high among certain cancers, such as brain and pancreatic cancers<sup>102</sup>, and certain patient groups, such as teenagers and young adults where rates increase to 37%<sup>103</sup>

Even when adjusting for factors such as stage of diagnosis, age at diagnosis and the presence of co-morbidities, emergency presentation is associated with a worse prognosis in the first year after diagnosis<sup>104</sup>. It is therefore extremely important to better understand how and why patients present as emergencies, and what action can be taken to minimise the number of cases that are diagnosed in this way.

In 2010, there was almost a fourfold variation between GP practices in the number of urgent referrals made to specialists for suspected cancer<sup>105</sup>. This is greater than would be expected due to variation in case mix and population difference.

### Variation in urgent GP referral rates (two week wait)

In 2010, the National Audit Office identified that, among former primary care trusts, there was almost a four-fold variation between GP practices in the number of urgent referrals made to specialists for suspected cancer, which can be seen in the figure below<sup>106</sup>. This is greater than would be expected due to variation in case mix and population difference.

It is not necessarily true that higher rates of referral are 'better', as both under- and over-use of urgent referrals can potentially cause challenges: referring too few patients can lead to delayed referral and later diagnosis, while referring too many inappropriate cases could lead to delays for people who do need to be seen urgently. Action to further understand and reduce variation in referral rates is needed to ensure patients are able to access diagnostics as quickly and easily as possible when needed.



Figure 9: Variation in urgent GP referral rate per 100,000 (not age standardised) by PCT, 2010/2011<sup>107</sup>

#### PROGRESS IN IMPROVING EARLY DIAGNOSIS

Understanding the causes of diagnostic delay is important for developing effective solutions. Delay in seeking medical care can be combated by awareness campaigns; delays in primary care could be tackled by education or enhanced provision of investigations; hospital delays are generally countered by improved organisation of services<sup>108</sup>. A number of initiatives have been implemented to improve early diagnosis since the publication of the *NHS Cancer Plan* in 2000, with some progress.

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### Reducing patient delay: The National Awareness and Early Diagnosis Initiative

The International Cancer Benchmarking Partnership (ICBP) revealed that more people in the UK than other country cited specific reasons for not visiting their GP, even with a symptom that worried them. This included embarrassment and not wanting to waste their GP's time<sup>109</sup>.

The National Awareness and Early Diagnosis Initiative (NAEDI) was established following the Cancer Reform Strategy in 2007. It is led by NHS England, Department of Health, Public Health England and Cancer Research UK. It coordinates and supports activities that promote the earlier diagnosis of cancer in four work streams:

- achieving early presentation by public and patients
- optimising clinical practice and systems
- improving GP access to diagnostics
- research, evaluation and monitoring

Since its inception, NAEDI has led much of the work relating to early diagnosis in England. This work has been extremely valuable and should continue to be resourced appropriately in the future.

#### Reducing patient delay: Be Clear on Cancer

The International Cancer Benchmarking Partnership (ICBP) is a unique global partnership of clinicians, academics and policy makers. It is the first of its kind, seeking to understand how and why cancer survival varies between countries and jurisdictions<sup>110</sup>. The ICBP has shown that the British public are generally as aware of their cancer symptoms as people in other countries, but, crucially, they are less likely to see their GP than people in comparable countries – often because of concerns that they are wasting their GP's time<sup>111</sup>.

Be Clear on Cancer (BCOC) is a campaign to promote awareness and early diagnosis of cancer locally, regionally and nationally; but crucially it also aims to empower the public to see a doctor if they are worried. It was launched in 2010 as a NAEDI work stream. Since 2014, responsibility for BCOC sits within Public Health England.

Be Clear on Cancer campaigns go through a rigorous process to decide which will have the most impact. Pilots of a new campaign are run first on a limited, local basis to test effectiveness, before being implemented secondly across a region, and then finally nationwide. Recent campaigns have focused on lung cancer, kidney and bladder cancers, breast cancer, ovarian cancer, rarer cancers and bowel cancer. Of these, lung, bladder and kidney cancer campaigns are currently running nationwide<sup>112</sup>.

During the national Be Clear on Cancer lung cancer campaign, an extra 700 extra cases of lung cancer were diagnosed. 400 were at an earlier stage<sup>113</sup>.

Evaluation of the national BCOC campaigns shows that they have been highly successful in increasing awareness of symptoms and encouraging people to visit their GP if they are worried <sup>114</sup>. For example, during the national lung cancer campaign 700 extra cases of lung cancer were diagnosed. 400 were at an earlier stage, and around 300 received surgery, which is essential to improve survival <sup>115</sup>.

Other campaigns have also been shown to be successful in increasing awareness of symptoms and willingness to see a GP if the patient is worried. 57 per cent of women said the ovarian cancer campaign gave them new information<sup>116</sup>. Furthermore, after a separate regional pilot of a "blood in pee" campaign, there was a 28 per cent increase in two-week wait referrals for suspected urological cancer<sup>117</sup>. This led to a full roll-out in 2014.

The success of these campaigns is welcome and BCOC should continue to be funded, with campaigns proven to be effective at a local and regional campaign rolled out nationally as soon as possible. Future BCOC campaigns should consider how to raise awareness of the risks of developing cancer, particularly in those cases of cancer which can be symptomless.

### Reducing doctor and system delay: Publication of CCG-level survival data

The All Party Parliamentary Group on Cancer has been campaigning for the publication and use of local data on one-year survival rates for many years<sup>118</sup>. This was published by the Office of National Statistics in December 2013<sup>119</sup> and presented as part of the Clinical Commissioning Group Outcomes Indicator Set in June 2014<sup>120</sup>.

Regular publication of this data is a big step forward for transparency in cancer outcomes, and it will be useful to support changes in commissioning and clinical practice at a local level to improve early diagnosis across England. As far as possible, this data should also be presented in such a way as to highlight variations between groups, for instance by age and gender. Where results would be statistically significant, data should be broken down according to cancer type. In addition, we strongly recommend that one-year survival rates should be included within the Delivery Dashboard, which forms part of the Clinical Commissioning Group Assurance Framework and is published by NHS England. This will ensure that these data underpin assurance conversations between CCGs and NHS England area teams, driving continued improvements in local one-year survival rates<sup>121</sup>.

"As a cancer community we have to ensure that progress is built upon...we can't take anything for granted"

John Baron MP, Chair of the All-Party Parliamentary Group (APPG) on Cancer1<sup>22</sup>

The Cancer Campaigning Group strongly supports the All Party Parliamentary Group on Cancer (APPGC)'s focus on transparency and accountability. We hope MPs will take up the challenge set by the APPGC to use their local data to hold cancer services to account for their constituents, in particular to promote earlier diagnosis.

### Reducing system delay: Funding for, and consistent access to, diagnostic tests

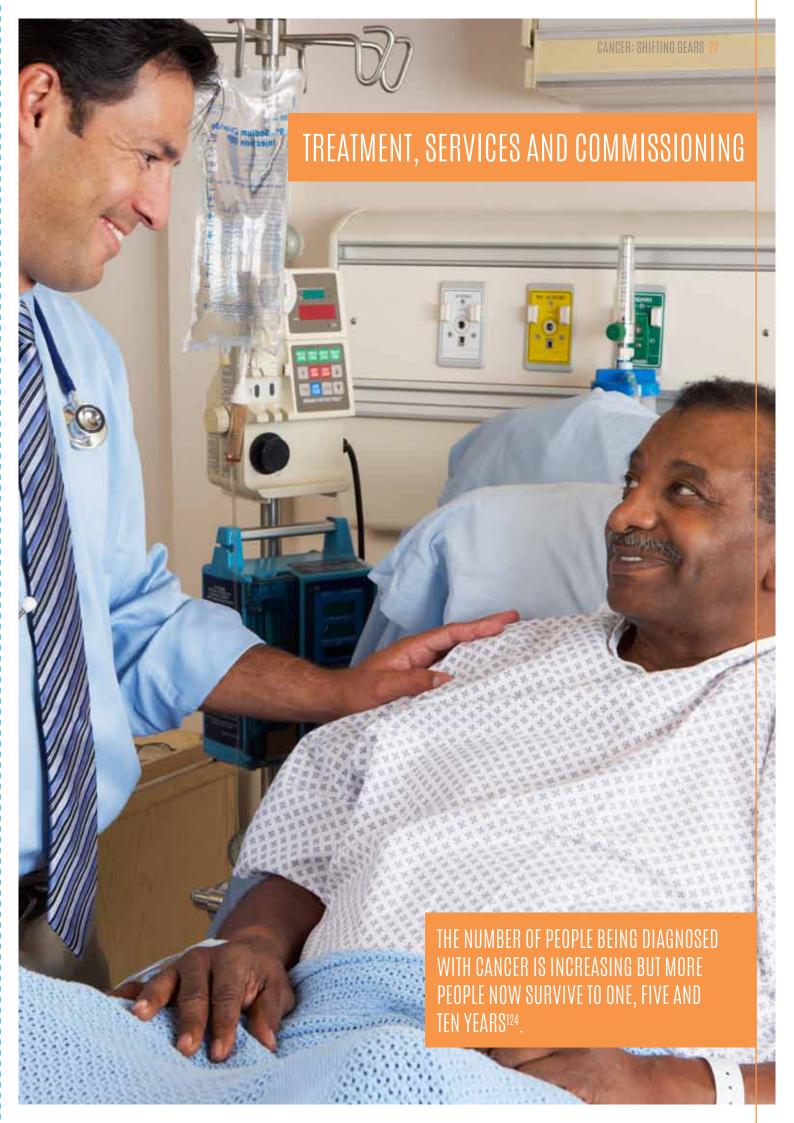
Patients with cancer symptoms that meet clinical guidelines should always be referred via the two-week wait pathway. However, many cases of cancer have more subtle symptoms, that a GP might feel require further investigation but don't merit an urgent referral. In some cases giving GPs direct access to diagnostic tests can be helpful and where this is the case they should be available.

More than £450 million was invested as part of *Improving Outcomes: A Strategy for Cancer* to support earlier diagnosis. Part of this was intended to increase GP access to four key diagnostic tests for cancer: non-obstetric ultrasound, chest x-ray, flexible sigmoidoscopy and brain MRI<sup>123</sup>. This additional funding was welcome, but the Cancer Campaigning Group would like to see evidence of its impact.

We welcome the use of risk assessment tools to support GPs to detect cancer earlier - such as the Cancer Decision Support Tool, which we hope to see used more widely. Consideration should continue to be given to other, innovative means of promoting early diagnosis of cancer.

#### OUR VISION FOR THE FUTURE OF AWARENESS AND EARLY DIAGNOSIS

Early diagnosis represents one of the biggest opportunities to improve cancer outcomes. We are calling on political leaders to reiterate their support for national leadership on early diagnosis, including the Public Awareness campaigns run through the National Awareness and Early Diagnosis Initiative. The NHS and public health systems must work effectively to help people to recognise the symptoms and signs of cancer and encourage them to seek advice from their GP or other healthcare professional as soon as possible. Timely access to diagnostic tests where cancer is suspected is essential and GPs must be given more support to recognise cancer symptoms and refer people appropriately for further investigations.



### TREATMENT, SERVICES AND COMMISSIONING

Early access to effective treatment – including surgery, radiotherapy and anti-cancer medicines – has a crucial role to play in improving the UK's cancer survival rates. Moreover, overall coordination of treatment – which is integrated around, and responsive to, a patient's needs – not only supports improved patient outcomes but can also improve experience of care. However, assessments of quality and access to cancer treatments have highlighted that variation of access, often related to the age of the patient, remains an enduring challenge.

#### **EVIDENCE OF VARIATION**

Evidence of variation in quality of care	Evidence of poorer care for older people
National clinical audits (bowel cancer, head and neck cancer, lung, oesophago-gastric cancer (various), Health and Social Care Information Centre	Improving outcomes and experiences for older women with breast cancer: A policy briefing by Breast Cancer Care (2011), Breast Cancer Care
National Cancer Peer Review Programme (from 2001), hosted by NHS England as of 2013	Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project (2012), Macmillan Cancer Support, the Department of Health and Age UK
Inquiry into tackling cancer inequalities (2009) and Tackling cancer inequalities - one year on (2010), All-Party Parliamentary Group on Cancer	Access all Ages: Assessing the impact of age on access to surgical treatment (2012), Age UK, MHP Health and The Royal College of Surgeons
Atlas of Variations (2010 and 2011), Right Care	The age old excuse: The under treatment of older cancer patients (2012) Macmillan Cancer Support
Cancer Patient Experience Survey (from 2010), Department of Health	Age is just a number: The report of the parliamentary inquiry into older age and breast cancer (2013), All-Party Parliamentary Group on Breast Cancer, Breakthrough Breast Cancer, Breast Cancer Care and the Breast Cancer Campaign
The radiotherapy innovation fund: An evaluation of the Prime Minister's £23 million fund (2013), Cancer Research UK, The Royal College of Radiologists, The College of Radiographers, Institute of Physics and Engineering in Medicine	Are older people receiving cancer drugs? An analysis of patterns in cancer drug delivery according to the age of patient (2013), NHS England and the Association of the British Pharmaceutical Industry
An evaluation of cancer surgery services in the UK (2014), Cancer Research UK	
Atlas of Variations in Diagnostic Services (2014), Public Health England and Right Care	

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## INITIATIVES TO IMPROVE THE QUALITY, COORDINATION AND ACCESS TO TREATMENT AND SERVICES

#### **Multi-disciplinary teams**

The wide-scale rollout of Multi-Disciplinary Teams (MDTs) since 2000 has made a major difference to how cases of cancer are managed collaboratively. These were formally set up to help the different healthcare professionals involved in an individual's care to better manage that patient. Among other things, an MDT can:

- help ensure individuals receive accurate diagnosis and testing;
- provide tailored and comprehensive information about treatments and local services;
- include psycho-social elements of care through the involvement of allied health professionals;
- offer coordination and continuity of care<sup>125</sup>

"One of the most significant achievements since 2000 is the concept of a cancer pathway, so patients run smoothly from referral, all the way through their journey - from diagnosis through the various stages of treatment... They are now seen as a continuum."

Professor Julietta Patnick CBE, Director, NHS Cancer Screening Programmes126

The MDT has now become a central tenet of cancer services and is held in high regard internationally. Furthermore, the introduction of MDTs with particular specialties, such as teenage and young adult MDTs, have helped to ensure care is tailored appropriately for patient groups. As a result, variation in practice has reduced over time, helped in part by the National Cancer Peer Review Programme which has reported annually on the quality of services 127. The Programme must be continued and protected, and more information is needed on proposed changes to Peer Review to ensure these do not impact patient safety or outcomes.

#### **Waiting time targets**

The NHS Constitution guarantees the right to access certain services commissioned by NHS bodies within maximum waiting times <sup>128</sup>. Cancer waiting times were introduced in the 2000 NHS Cancer Plan and the 2007 Cancer Reform Strategy and retained in the 2011 Improving Outcomes: A Strategy for Cancer. Shorter

waiting times can help to ease patient anxiety and, at best, may lead to earlier diagnosis, quicker treatment, a lower risk of complications, an enhanced patient experience and improved cancer outcomes<sup>129</sup>.

There are currently eight cancer waiting time targets, which include:

- 93 per cent of patients waiting a maximum of two weeks to see a specialist after urgent referral by a GP for suspected cancer
- 96 per cent of patients waiting a maximum of 31 days (one month) between receiving their diagnosis and starting treatment
- —85 per cent of patients waiting a maximum of 62 days (two months) between an urgent GP referral for suspected cancer and starting treatment

During Q4 2013-14 and Q1 2014-15, the NHS slipped below the target of 85 per cent of patients waiting a maximum of 62 days between an urgent GP referral and starting treatment 130,131. This is the first time the target has been breached since it was introduced in 2009.

For the first time since it was introduced in 2009, the NHS in England has slipped below the latter target for the last two consecutive quarters. In Quarter 4 2013-14, 84.4 per cent of cancer patients began treatment within 62 days of an urgent GP referral<sup>132</sup>. In Quarter 1 2014-15, this has fallen further to 84.1 per cent of people<sup>133</sup>. This represents the first breach of any of the cancer waiting time targets since they were introduced. Increasing delays in initiating treatment are putting people's lives at risk and pose the danger of a further decline in the UK's comparatively poor survival rates.

#### Surgery

There have been continued improvements in access to and quality of cancer surgery. Nearly half of all people who are cured of cancer now have surgery as part of their treatment<sup>134</sup>. Surgery also plays a role in prevention, diagnosis and symptom management<sup>135</sup>.

In order to better understand persisting variation in access to, and quality of, surgery, NHS England has committed to publish surgeon level outcomes data across a range of surgical interventions<sup>136</sup>. This is a welcome step forward in increasing transparency and understanding local commissioning and clinical practices. However, reporting currently covers only a limited number of procedures. Queries also remain

about how easy this data is to interpret and whether an inadvertent impact of making data publically available is to make surgeons more risk averse<sup>137</sup>. NHS England should continue to gather and publish data on cancer surgery, but must also give consideration to how this data can be gathered and presented in a way which is most useful for people with cancer as well as commissioners.

#### Radiotherapy

Radiotherapy is second only to surgery in its effectiveness in treating cancer, with estimates suggesting that four in ten patients whose cancer is cured receive radiotherapy<sup>138</sup>. The Radiotherapy Innovation Fund (RIF) boosted access to Intensity Modulated Radiotherapy (IMRT), an advanced form of radiotherapy which is more targeted at the patient's cancer and causes less damage to surrounding healthy tissue. In August 2012, only 13.6% of patients receiving radiotherapy in England were given IMRT. By January 2014 this had risen to 32%<sup>139</sup>.

More patients should continue to benefit from this form of radiotherapy. Around 50 per cent of people with cancer should receive radiotherapy as part of their treatment<sup>140</sup>. NHS England should make long-term plans to ensure that the necessary infrastructure is in place to meet growing future need for radiotherapy, including new equipment and trained staff. The NHS must be prepared to adopt other advanced and innovative radiotherapy techniques when these are proven to be clinically and cost-effective<sup>141</sup>.

In August 2012, only 13.6% of patients receiving radiotherapy in England were given IMRT. By January 2014 this had risen to 32%.

#### **Cancer Drugs**

The Cancer Campaigning Group is disappointed that plans to incorporate a wider measure of value into NICE's appraisal methodology, via value based assessment, has been indefinitely delayed. The Cancer Campaigning Group would like NICE to conduct its wider review into the appraisal of medicines as quickly as possible and take steps to improve access to cancer medicines as a priority.

The CDF has benefitted over 55,000 patients in England who would not otherwise have had access to the same treatment<sup>142</sup>.

The formation of the Cancer Drugs Fund (CDF) in 2010 has widened access to a range of cancer drugs, particularly those for rarer cancers and those for use at the end of life when certain circumstances are met – including those which have been rejected during the NICE appraisal process. As such, the CDF has benefitted over 55,000 patients in England who would not otherwise have had access to the same treatment<sup>143</sup>. It is hopes that the forthcoming Systemic Anti-Cancer Therapy Database (SACT) will help to address the lack of data on the clinical impact of this access.

The Cancer Drugs Fund will only run until 2016 and due to a £40 million budgetary overspend in 2013/14, the Fund has recently been granted an extra £80 million for each of the next two years 144. At time of writing, NHS England is consulting on its Standard Operating Procedure for making treatments available through the Fund. Any proposals to re-assess the value of drugs funded by the CDF must take into account evidence of their performance in the general population since their original appraisal decision. Moreover, despite the temporary increase in funding, a longer-term solution is needed which will ensure that people with cancer can continue to access the best, evidenced-based treatments for their condition.

Newer cancer drugs are also becoming increasingly targeted and are accompanied by tests to establish which patients will most benefit from them. These tests are not routinely available throughout the NHS at present, and extending access to these assessments will be the next step towards realising the full benefits of stratified medicine in the coming years.

#### End of life care

In 2008, the Department of Health published the national *End of Life Care Strategy*<sup>145</sup>. This has since been updated every year, with responsibility for updating the Strategy now transferring to NHS England. Supported now by the NICE quality standard for end of life care, published by NICE in August 2011<sup>146</sup>, clear guidance is in place for CCGs to design services which meet the range of needs for people with cancer at the end of their life. Ever closer care planning and delivery between NHS and social

care will be central to making this a reality and the implementation of the Better Care Fund may have a role to play here. In addition, CCGs should implement the Electronic Palliative Care Coordination Systems<sup>147</sup> and provide 24/7 nursing support.

#### COMMISSIONING CANCER SERVICES IN THE NHS

Cancer commissioning has undergone substantial changes in recent years. April 2013 brought new structures into effect:

- Clinical commissioning groups have responsibility for commissioning common cancer services as well as early diagnosis, services for patients living with and after cancer as well as end of life care
- NHS England has responsibility for the direct commissioning of specialist services including chemotherapy and radiotherapy, primary care and cancer screening
- Public Health teams within Local Authorities take on responsibility for prevention and population awareness of cancer signs and symptoms

Given the split in commissioning responsibility, further guidance on the specific responsibility of CCGs for commissioning common cancer services would be welcome. With the disbanding of cancer networks and the broadening remit of SCNs along with a reduction in their staffing and funding, it is vital that specialist, dedicated cancer expertise is not lost. CCGs should continue to receive expert advice and support, including by appointing a named cancer lead and through support from tumour site-specific groups.

NHS England is supported in the commissioning of cancer services by expert Clinical Reference Groups (CRGs), made up of stakeholders who have direct experience of cancer services. The expertise of these groups has brought welcome insight to the commissioning of specialised cancer services, though sufficient resourcing as well as further transparency on the workings and priorities of these groups would be welcome.

In spring 2014, further changes to increase joint local commissioning have been proposed by the new NHS England Chief Executive, Simon Stevens. While the plans are still in the early stages of development, they may mean more joint decision-making between CCGs and NHS England area teams, clinical commissioning groups carrying out functions on behalf of NHS England and, potentially, pooled

funding arrangements<sup>148</sup>. These arrangements have the potential to help achieve more integrated care journeys for a cancer patient, one which is coordinated around, and responsive to, their needs, regardless of setting.

During 2012, the Cancer Campaigning Group undertook a survey of over 350 patients and carers. Headline improvements that patients wanted to see included:

- Securing quicker referral from GPs to hospitals for testing and diagnosis
- Ensuring patients find out the results of their tests as quickly as possible
- Providing patients with access to a named clinical nurse specialist or other 'key worker' throughout the care pathway
- Supporting patients to feel involved in key decisions about their treatment and care
- Putting systems in place to make sure records and test results are available to all clinicians and staff involved in patients' care

In light of these findings and national commitments to deliver increasingly holistic and integrated NHS and social care services, commissioners and providers must be supported to design and deliver integrated cancer services that are coordinated seamlessly around the needs of a patient. This may be a particular challenge for service specifications for children and teenagers and young adults with cancer who access out-of-area principal treatment centres. National and local organisations, including CCGs, health and wellbeing boards and strategic clinical networks have an important role to play in making this a reality to improve people's experiences of care and their quality of life.

### Assessing the impact of new commissioning structures

In their recent report, *Measuring up? The Health of NHS Cancer Services*, CRUK argued that there is a real need to "review both the leadership and commissioning of cancer services so they are fit to meet the looming demands of an ageing population and the predicted rapid increase in cancer cases" 149. Key opportunities to assess the impact of these changes include measuring outcomes and experiences of care:

#### Measuring outcomes

The crucial test of the NHS reforms will be whether they truly deliver integrated care pathways that improve outcomes and experiences of care for people with cancer. The NHS Outcomes Framework 2014/15<sup>150</sup> and Public Health Outcomes Framework 2013-16151 include an indicator on mortality rates in under 75s and the datasets are starting to assess progress. In addition, the NHS Outcomes Framework 2014/15 includes indicators on one- and five-year survival from all cancers; one- and five-year survival from breast, lung and colorectal cancer; and five year survival from all cancers in children<sup>152</sup>. The Public Health Outcomes Framework 2013-16 includes further indicators on cancer diagnosed at stage 1 and 2, and cancer screening coverage<sup>153</sup>. Finally, to assess outcomes at CCG level, data on one-year survival from all cancers and one-year survival from breast, lung and colorectal cancer were published, first by the Office of National Statistics and then in June 2014 as part of the CCG Outcomes Indicator Set<sup>154</sup>.

The Cancer Campaigning Group supports this focus on outcomes and hopes the data published will be used to drive continued improvements in the quality of services. We further hope these outcome measures will be strengthened, including by adding one-year survival rates to the Delivery Dashboard, to underpin assurance conversations between CCGs and NHS England area teams and drive continued improvements<sup>155</sup>. In addition, compliance with NICE quality standards should be monitored to hold providers and commissioners to account for the quality of services. Sufficient data collection initiatives are essential to make this a reality.

#### Measuring patient experiences of their care

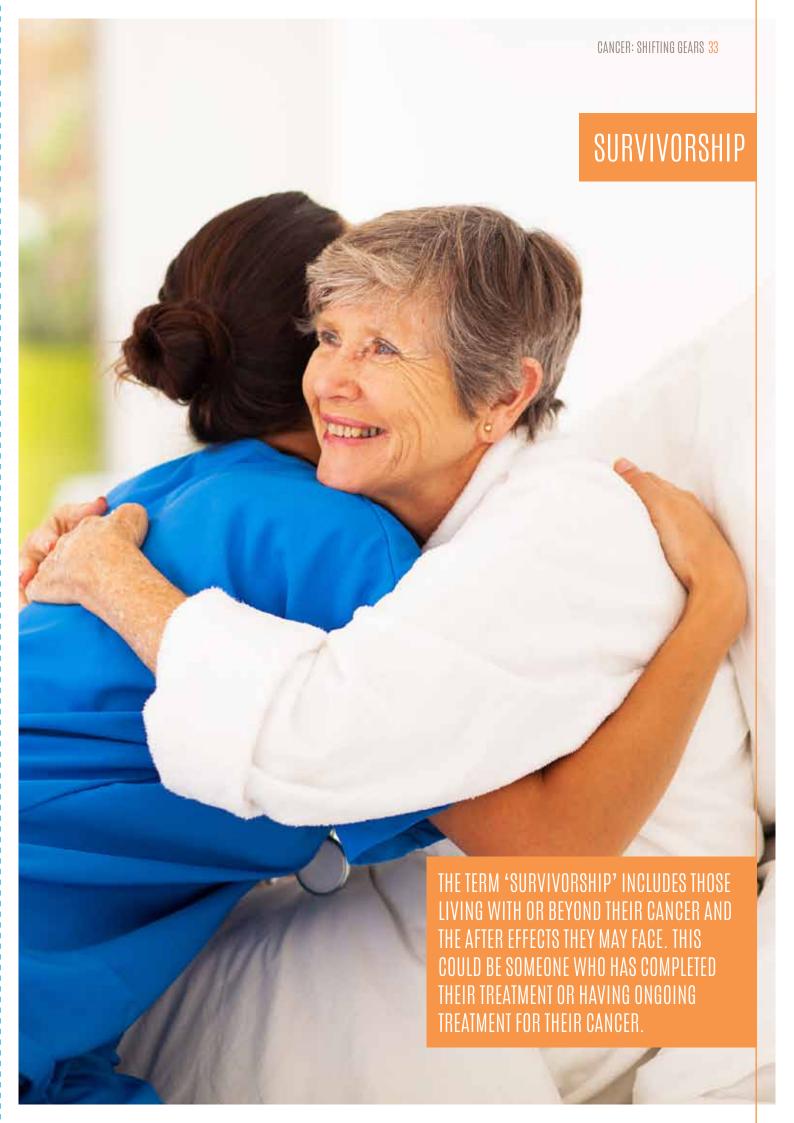
In 2007, the Cancer Reform Strategy established a new NHS Cancer Patient Experience Survey (CPES) Programme to monitor national progress and to use the findings to drive quality improvements locally. Since the first iteration in 2010, this has greatly improved understanding of cancer patients' experience of their treatment and where poor performance occurs most often.

Since 2010 the surveys have demonstrated some improvements, though it is clear that significant progress is still required in some areas. The CPES should continue to be published annually to increase transparency and scrutinise care standards. It should also expand in scope to include an additional survey about care for those aged between 0 and 25 years of age. This will be an important measure for the impact of the new structures. Furthermore, clinical commissioning groups should ensure that they are monitoring and acting upon the findings of the surveys, particularly where cancer patient experience is identified as being particularly poor. All CCGs where patient experience is poor should work to develop strategies to improve their local performance, as should NHS England for those specialised services it commissions nationally.

The Cancer Patient Experience Survey Programme was established in 2007 to help monitor quality of care. In 2013 NHS England estimated that 116,000 cancer patients had completed the survey, offering valuable information to build an understanding of the quality of care patients are receiving<sup>156</sup>.

#### OUR VISION FOR THE FUTURE OF TREATMENTS, SERVICES AND COMMISSIONING

People with cancer should be able to access the full range of clinically appropriate and evidence- based treatments and services. While national commissioning for some cancer should be protected, the Cancer Campaigning Group hopes that commissioning decisions will be brought closer to the patient, with personalised care plans having an important role to play. The provision of clear and age-appropriate information and advice can support high quality decision-making and treatment, and is essential to ensuring patients can access the best services. This requires national, regional and local leadership in cancer services to be adequately resourced and supported.



### SURVIVORSHIP

There are currently 2 million people living with or beyond cancer in the UK. This figure is expected to double to 4 million by 2030<sup>157</sup>, with half of all cancer patients now surviving at least ten years<sup>158</sup>. The NHS will need to be more effective and efficient in the way it meets the range of needs of people with cancer during and after their treatment.

#### Challenges that cancer survivors may face<sup>159</sup>

People who have finished treatment may experience a range of difficulties returning to normal life. They may:

- struggle emotionally, needing to adjust to changes treatment has made to their body
- have to cope with short-term and long-term side effects of their cancer or its treatment
- have to live with the knowledge that their cancer cannot be cured, even though they feel healthy
- have difficulties accessing information about their condition or any after effects they may experience
- struggle financially as the household income decreases
- experience problems returning to the workplace

#### THE NATIONAL CANCER SURVIVORSHIP INITIATIVE

The National Cancer Survivorship Initiative (NCSI) was established in 2008 as a result of the Cancer Reform Strategy. Run until March 2013 as a partnership between the Department of Health and Macmillan Cancer Support, with support from NHS Improvement, the NCSI's vision was for "those living with and beyond cancer to get the care and support they need to lead as healthy and active a life as possible, for as long as possible."

During 2013, the NCSI published *Living with and beyond cancer: Taking action to improve outcomes*<sup>161</sup>. This document, intended to support commissioners, providers and others to improve survivorship outcomes, describes interventions that have been tested and are ready to spread immediately across England. This includes the introduction of an integrated package of interventions, The Recovery Package helps people and their healthcare professionals to prepare for the future, identifying individual needs and discussing how to return to work (if they choose) and a near normal lifestyle after a cancer diagnosis. The Package includes:

- Structured Holistic Needs Assessment and Care Planning
- A Treatment Summary and Cancer Care review
- Patient education and support events (Health and Wellbeing Clinic)
- Advice about and access to schemes that support people to undertake physical activity, healthy weight management, and manage the potential consequences of their cancer treatment

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The Recovery Package helps people to prepare for the future, identify their individual needs and return to work or a near normal lifestyle after a cancer diagnosis<sup>163</sup>.

The NCSI focused on implementing this widely throughout the NHS and believed this could have a real impact on the experiences of people living with a cancer diagnosis and particularly after initial treatment has finished. In particular, all efforts should be made to promote a healthy and active lifestyle for people with and beyond cancer, for instance by promoting physical activity, which studies have shown people spend less time in hospital and make fewer visits to their GP<sup>164</sup>.

The 2013 National Patient Experience survey found that "the impact of the CNS is overwhelmingly positive. On questions introduced in 2012 and in 2013, such as on care plans and the overall rating of care, the evidence is also very strong that having a CNS makes a measurable impact on the care that patients receive" 165.

Following on from the success of the NCSI, NHS England and Macmillan Cancer Support are now leading the *Living With and Beyond Cancer Programme*, a two year partnership to develop and implement a transitional plan for the National Cancer Survivorship Initiative. The Cancer Campaigning Group looks forward to opportunities to support this Programme to embed high quality support for cancer survivors into NHS commissioning and service provision.

#### The role of clinical nurse specialists

Clinical nurse specialists (CNSs) are ideally placed to provide tailored support to patients throughout their cancer pathway. This includes the development of personalised care plans for cancer survivors, which is particularly crucial when initial cancer treatment has finished, to help address a patient's physical, psychological, social, practical, financial and spiritual needs. As demonstrated through the findings of the National Cancer Patient Experience Survey 2013<sup>166</sup> and Macmillan<sup>167</sup>, CNSs contribute to improved outcomes and experiences of patients, as well as potentially saving the NHS significant amounts of money<sup>168,169</sup>.

Recent findings published by CRUK found that constrained resources were having an impact on existing healthcare professionals' workloads, including among CNSs – with these nurses sometimes seen as an opportunity to make cost savings<sup>170</sup>. The Government should firmly commit to maintaining and supporting the roles of CNSs, and increasing the number of nurses specialising in treating patients with secondary cancer.

#### OUR VISION FOR THE FUTURE OF SURVIVORSHIP

With England's cancer survival rates on a welcome increase, far more should be done to support the growing number of people living with and beyond cancer to improve their quality of life. The Cancer Campaigning Group hopes that every cancer patient will be offered the Recovery Package which includes a holistic needs assessment and written care plan to ensure that their full range of needs are met.

We also hope that every cancer patient should be offered a recovery package which includes a holistic needs assessment and written care plan, through the National Cancer Survivorship Initiative.



# RESEARCH

Cancer research is the only way to ensure that we beat all cancers. Understanding the basic science of cancer — why it starts, how it develops, how it can be detected and how it can treated — enables us to better prevent, diagnose and treat the disease. With the number of people living with cancer set to double to four million by 2030, cancer research can help ensure that England's survival rates continue to improve.

The UK has an excellent scientific research base and has spent a number of years developing a world leading data resource led by the National Cancer Intelligence Network. We also have among the highest rates of recruitment into clinical trials – higher than any country in Europe or the USA<sup>172</sup>. The challenge is how to protect this expertise and build on it further to ensure that patients in the UK can receive the most effective care possible, at the earliest stage they can.

"Cancer research has benefited from a strong commitment to working in partnership across organisations, across research institutes, and with the active involvement of patients and carers.

We've seen considerable progress, and there could be a temptation to say that cancer has been done and we have to move on to other areas. But keeping the momentum going is vital to ensure patients can benefit from research advances that will help them to overcome this complex disease."

Dr Karen Kennedy, Director, National Cancer Research Institute  $^{\rm 177}$ 

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2003 2004 2005 2006 2007 2008 2009 2010 2011 2012

The National Cancer Research Institute (NCRI) was

formed in 2001 following commitments set out in

the NHS Cancer Plan. One of the NCRI's roles is to

collate the total spending on cancer research from

its 22 partner organisations, spanning government

cancer research grew steadily from £257 million in 2002 to £507 million in 2012. Whilst this represents

a near doubling, investment levels have started to

organisations, charities and pharmaceutical

industry. As Figure 11 illustrates, investment in

Figure 10: Research spend of NCRI members, 2002-2012<sup>175</sup>

# FUNDING FOR BASIC SCIENCE AND MEDICAL RESEARCH

Medical research in the UK benefits from a unique combination of Government, charity and industry partners. Government investment in science is key to leveraging the other investment and partnerships on which the UK medical research base is built<sup>173</sup>.

Investment in cancer research grew steadily from £257 million in 2002 to £507 million in 2012 - but levels have started to plateau in recent years<sup>174</sup>.

The Government should, at the very least, maintain its current spend on science. It should also continue to support charity funded medical research, by maintaining the Charity Research Support Fund – a resource that means that the indirect costs of research are met by universities when charities fund the direct costs. This will help maintain the UK's world-class science base and facilitate collaboration, allowing the UK to continue to pioneer the development of cures for all cancers. This is vital to maintain our enviable position at the forefront of global medical research.

# A RESEARCH-RICH AND COLLABORATIVE INFRASTRUCTURE

Partnership work between charities, industry, universities and Government has been vital to maximise the impact of cancer research. In 2013/14 Cancer Research UK, for example, spent £386 million on research in institutes, hospitals and universities across the UK, including the Francis Crick Institute<sup>177</sup>. A number of welcome initiatives over recent years have sought to develop a collaborative and research-driven infrastructure, which must be maintained.

# The British public donated an estimated £1.7 billion to medical research charities in 2012/1376.

The Experimental Cancer Medicines Centres (ECMCs) were established in 2006 to drive developments in the discovery, development and testing of bio-markers and anti-cancer therapies. The Centres are jointly supported by Cancer Research UK and the health departments for England, Scotland, Wales and Northern Ireland. They bring together leading figures from multiple organisations in early-phase clinical research and world-class infrastructure. To date, the ECMC initiative has supported over 2000 studies, including early phase trials of new biological therapies<sup>178</sup>.

The UK has set an ambition to be a global leader in stratified medicines<sup>179</sup> – aiming to personalise the diagnosis and treatment of individual patient cohorts rather than broader, often heterogeneous, disease groups. As part of this, the Cancer Research UK Stratified Medicine Programme has been established as a partnership between Cancer Research UK, Astra Zeneca, Pfizer and the Technology Strategy Board. The Programme aims to establish how the NHS can undertake standardised, high quality, cost-effective genetic testing of tumours, helping patients receive more targeted medicines as these become available. A pilot phase was led by eight Experimental Cancer Medicines Centres, testing up to 9,000 patients' samples by June 2013, and further phases are in train<sup>180</sup>.

The Health and Social Care Act 2012 includes a statutory duty for NHS England and CCGs to promote and support research in the NHS<sup>181</sup>. This is a welcome move, and CCGs and NHS England must ensure that they have representatives on their respective boards with a responsibility for the promotion and support of research. Academic health science networks (AHSNs) are well placed to drive a culture of collaboration in

their locality as well as support the spread of research to improve patient outcomes, and should report on progress annually. The Care Act 2014 supported the creation of the Health Research Authority, which will be instrumental in streamlining clinical trials, enabling the UK to remain a world leader in this area.

# CLINICAL TRIALS: RECRUITMENT, REGULATION AND PATIENT INVOLVEMENT

#### Regulation

A recent report shows the average time lag between investment in cancer research and eventual impact on patients is around 15 years<sup>183</sup>. The efficient regulation of clinical trials, including multi-centre trials, is crucial to minimise delays in their set up and recruitment of patients. Lessening the bureaucratic burden – without compromising on safety – is essential in continuing to develop the UK's leadership credentials in this area. The Health Research Authority will focus on reducing this burden as a priority, which the Cancer Campaigning Group warmly supports. Furthermore, the Group supports the improvements set out in the European Clinical Trials Regulation and hopes these will be realised in its implementation, expected in 2016.

The average time lag between investment in cancer research and eventual impact on patients is around 15 years<sup>182</sup>.

#### Recruitment

The original aim of the NCRI was to double the number of cancer patients taking part in clinical studies in England within five years – this target was reached by 2004, in just three years <sup>184</sup>. Now, more than one in five adult cancer patients in the UK take part in a clinical trial, representing a higher proportion than anywhere else in the world <sup>185</sup>. The UK should be proud of this achievement, but further progress could still be made.

In 2013 just 33 per cent of patients stated that someone discussed participating in cancer research with them. Of the remainder, 53 per cent said they would have wanted to discuss it <sup>187</sup>. Among urological cancer patients, this figure was as low as 16 per cent, with the best results, 38 per cent, seen in brain/CNS cancer patients <sup>188</sup>. In order to further strengthen the UK's world-leading clinical trial participation rates, clinical staff need to be encouraged, with appropriate training, to offer the opportunity to participate in clinical research to all patients where it is appropriate to do so.

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In 2013 just 33 per cent of patients stated that someone discussed participating in cancer research with them. Of the remainder, 53 per cent said they would have wanted to discuss it<sup>88</sup>.

In addition, more could be done to ensure that patients with clinically rarer cancers are provided with similar opportunities and encouraged to access clinical trials<sup>189</sup>. Furthermore, age restrictions mean that many young people miss out on clinical trials. In order to maximise participation in clinical trials, researchers should be asked to clearly justify age restrictions on new studies, which will ensure that any such restrictions are only in place when necessary.

#### Patient involvement

Through the NCRI and NCRN, the UK has led the way worldwide in involving patients in decision-making in cancer research. The NCRI Consumer Liaison Group was founded in late 2001 and approximately 250 patients and carers have been members over the years. Patient involvement in the design, development and management of cancer studies has been a part of the success story of cancer research in recent years. However, funding uncertainty means the future of patient involvement after April 2015 is in doubt, a question which must be resolved if the UK is to continue to be at the forefront of effective patient involvement in cancer research.

#### DEVELOPING AND USING DATA

The National Cancer Intelligence Network, now operated by Public Health England, was launched in June 2008 following commitments in the *Cancer Reform Strategy*. The organisation aims to promote data collection, provide a national repository for cancer datasets and analysis, use information to improve cancer care and support audit and research programmes.

Since being formed, the NCIN has focused on linking datasets and developing a modern cancer registry. Its model has been so successful in highlighting issues such as variations in care and routes to diagnosis, that it is being replicated by Public Health England into other disease areas.

The National Cancer Registration Service now holds staging data on more than 80 per cent of all cases of the most common cancers, making it "one of the most advances anywhere in the world" 100.

Most recently, the NCIN published stage-specific one-year survival data in England for breast, lung, prostate, colorectal and ovarian cancer<sup>191</sup>. Its National Cancer Registration Service now holds staging data on more than 80 per cent of all cases of the most common cancers, making it "one of the most advanced anywhere in the world"<sup>192</sup>. The resource will be used to measure the effects of the National Awareness and Early Diagnosis Initiatives such as the Be Clear on Cancer Campaign.

The NCIN must continue to be adequately funded and it is vital that data gathered by the NCIN is used to drive further research into cancer diagnosis and treatment as well as more effective and informed commissioning.

"We have a unique resource...there's nobody in the world that has the granularity of the data, the rapidity of the data, the clinical relevance of the data, and the infrastructure to manage it that we have. Unless we make best use of that, we would be doing a disservice to patients and the families who have been through cancer diagnosis and treatment."

Chris Carrigan, Director of the National Cancer Intelligence Network<sup>193</sup>

#### OUR VISION FOR THE FUTURE OF RESEARCH

The UK should rightly be proud of our position as a world-leader in scientific research and medical innovation, and the contribution of charities, industry, Government, academic institutions and the NHS are vital to maintaining this position. Sustained investment in research – including maintaining the Government's science budget – as well as the appropriate infrastructure and opportunities for effective collaboration are vital to driving leading research. The UK should maintain and build on its leading recruitment rates to clinical trials, with further efforts made to reduce the administration requirements surrounding clinical trials and proper funding provided nationally to ensure effective patient involvement. Ultimately, the UK's world-leading science base must translate research into significant clinical outcomes which benefit patients as early as possible.

# CONCLUSION: PROTECTING AND BUILDING UPON PROGRESS TO DATE

This report has reviewed the substantial and welcome progress that has been seen in England across key areas of the cancer pathway over recent years. The impact of this is demonstrated, at a glance, through our improving survival rates.

However, there is increasing concern among the cancer community that this doesn't reflect the level of public concern and the reality of the cancer burden. Our survival rates highlight that we need to go much further if we are improve cancer care in the NHS and bring England's outcomes in line with the best in Europe.

The Cancer Campaigning Group's vision statements for each part of the patient pathway set out our ambition for the NHS, public health and social care systems to deliver world-leading cancer outcomes, with the best care for people with cancer, their families and carers. Government, the charity and voluntary sector, industry, the NHS and research and academic community must work collaboratively towards these goals. Fundamentally, strategic direction and leadership at the highest levels is essential to making these visions a reality.

The Cancer Campaigning Group urgently calls on all political parties to recognise and reiterate that England's cancer journey is far from complete. We want all political parties to continue to name cancer as a priority for the NHS, committing to strive for the best ahead of the 2015 General Election and beyond. We have set out three urgent recommendations for the next Government and NHS leaders to deliver during the 2015-2020 Parliament; actions which will improve experiences of treatment and care, improve quality of life for cancer survivors and save more lives – ultimately, bringing our cancer outcomes in line with the best in Europe.

#### STRATEGIC PLAN AND ANNUAL UPDATE

The next Government should work with NHS England to introduce a five-year strategic plan for improving cancer outcomes, so that they match the best in Europe. This must outline the long-term ambitions for cancer across the patient pathway, including benchmarks for success, and set out how the NHS, public health and social care systems will be supported, resourced, enabled and held accountable for achieving the best outcomes in Europe. The plan must be accompanied by an annual implementation update, assessing the progress made in the previous year and next steps to deliver the plan.

#### DATA

The NHS must continue to improve the scope and scale of data collection, using data to drive further research into personalised services and underpin more informed commissioning that is responsive to patient need and innovation. This will support the NHS to deliver evidence-based interventions and services, while measuring impact more effectively. A framework for maintaining and improving our data capabilities must be included within the strategic plan.

#### INTEGRATED CANCER SERVICES

Commissioners and providers must be supported to design and deliver integrated cancer services that are coordinated and seamlessly built around the needs of a patient. Improving patient experience should be central to this. The national strategic plan should outline the responsibilities for integrated cancer services, including the role that regional and local organisations can play.

The Cancer Campaigning Group looks forward to building on substantial progress made to date. We are keen to hear from policy makers and those involved in implementation in the NHS and public health systems to make these visions a reality. There is still a long way to go.

# ABOUT THE CANCER CAMPAIGNING GROUP

The Cancer Campaigning Group is a coalition of 60 cancer-related charities representing service providers, research, advocacy and campaigning groups for cancer patients and their families in England.

Founded in 2002, the Cancer Campaigning Group campaigns for world class research, prevention, diagnosis, treatment, support and care for every cancer patient in England to bring all services up to the standards of the best in Europe. At this crucial time in the development of health and cancer services, the Cancer Campaigning Group enables cancer charities to speak and campaign with a single, unified voice, pooling expertise, amplifying the impact of individual organisations, and ensuring that our messages are heard and acted upon by the Government and the NHS. More information is available on our website: www.cancercampaigninggroup.org.uk.

# THE CANCER CAMPAIGNING GROUP STEERING GROUP AND SECRETARIAT

The Cancer Campaigning Group's campaigning strategy and activities are developed by an elected Steering Group of representatives from six member charities – Cancer Research UK, CLIC Sargent, Macmillan Cancer Support, Prostate Cancer UK, the Rarer Cancers Foundation and the Roy Castle Lung Cancer Foundation. MHP Health provides the Secretariat to the Group, including communications advice, support and implementation.





























































#### SUPPORTERS

The Cancer Campaigning Group's work is supported by twelve pharmaceutical and diagnostic companies – Amgen, AstraZeneca, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Leo, Lilly, Novartis, Roche Products, Roche Diagnostics, Pfizer and Sanofi. Supporting organisations do not direct or control the Cancer Campaigning Group's strategy, activities or literature in any way. The Cancer Campaigning Group ensures that all its relationships with supporter organisations comply with the Association of the British Pharmaceutical Industry (ABPI) code of conduct, governing the relationship between patient groups and pharmaceutical companies.

#### CONTACT DETAILS

If you have comments or would like to discuss this report further, please contact the Cancer Campaigning Group's Secretariat on ccg@mhpc.com, who will direct your query to the Steering Group members.





























































# REFERENCES

- Cancer Research UK, Cancer statistics: key facts all cancers combined, May 2014. Available online via: http://publications. cancerresearchuk.org/downloads/Product/CS\_KF\_ALLCANCERS.pdf
- Cancer Research UK, Cancer statistics: key facts all cancers combined, May 2014. Available online via: http://publications. cancerresearchuk.org/downloads/Product/CS\_KF\_ALLCANCERS.pdf
- Maddams J et al. 'Cancer prevalence in the United Kingdom: estimates for 2008'. British Journal of Cancer 2009; 101:541-7. Available online via:: http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2720244/
- Cancer Research UK, Cancer survival for all cancers combined, April 2014. Available online via: http://www.cancerresearchuk.org/ cancer-info/cancerstats/survival/all-cancers-combined/
- Cancer Research UK, Cancer survival for all cancers combined, April 2014. Available online via: http://www.cancerresearchuk.org/ cancer-info/cancerstats/survival/all-cancers-combined/
- De Angelis, R. et al. (2013), 'Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study.' Lancet Oncology, 15 (1), pp. 23-34. Available online via: http://www.thelancet.com/%20journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext
- Calman K and Hine D, A policy framework for commissioning cancer services: Guidance for purchasers and providers of cancer services, April 1995. Available online via: http://www.dhcarenetworks.org. uk/\_library/Resources/ICN/Policy\_documents/Calman\_Hine.pdf
- Cancer Research UK, Cancer survival for all cancers combined, April 2014. Available online via: http://www.cancerresearchuk.org/ cancer-info/cancerstats/survival/all-cancers-combined/
- Cancer Research UK, Cancer survival for all cancers combined, April 2014. Available online via: http://www.cancerresearchuk.org/ cancer-info/cancerstats/survival/all-cancers-combined/
- De Angelis, R. et al. (2013), "Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study." Lancet Oncology, 15 (1), pp. 23-34. Available online via: http://www.thelancet.com/%20journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- NHS Choices, Information on cancer and useful links, June 2012. Available online via http://www.nhs.uk/conditions/Cancer/Pages/ Introduction.aspx
- Cancer Research UK, Cancer incidence for all cancers combined, January 2014. Available online via: http://www.cancerresearchuk. org/cancer-info/cancerstats/incidence/all-cancers-combined/
- Maddams J et al. 'Cancer prevalence in the United Kingdom: estimates for 2008'. British Journal of Cancer 2009; 101:541-7. Available online via:: http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2720244/
- Cancer Research UK, All Cancers (C00-C97), European Age-Standardised Mortality Rates, UK, 1971-2011, April 2013. Available online via: http://www.cancerresearchuk.org/cancer-info/ cancerstats/mortality/all-cancers-combined/
- Cancer Research UK, Cancer statistics key facts: All cancers combined, May 2014. Available online via: http://publications. cancerresearchuk.org/downloads/Product/CS\_KF\_ALLCANCERS.pdf
- Public Health England, 2014 Public awareness and opinion survey, July 2014. Available online via: https://www.gov.uk/government/ uploads/system/uploads/attachment\_data/file/342029/ PHE\_public\_opinion\_slide\_set.pdf

- Office for National Statistics, Cancer Survival. Available online via: http://www.ons.gov.uk/ons/taxonomy/index. html?nscl=Cancer+Survival
- Cancer Research UK, Cancer survival for all cancers combined, April 2014. Available online via: http://www.cancerresearchuk.org/ cancer-info/cancerstats/survival/all-cancers-combined/
- De Angelis, R. et al. (2013), "Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study." Lancet Oncology, 15 (1), pp. 23-34. Available online via: http://www.thelancet.com/%20journals/lanonc/article/PIIS1470-2045(13)70546-1 f/fullier
- Cancer Research UK, International Cancer Benchmarking Partnership: Module 1: Epidemiology. Available online via http:// www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/ Module-1/
- Calman K and Hine D, A policy framework for commissioning cancer services: Guidance for purchasers and providers of cancer services, April 1995. Available online via: http://www.dhcarenetworks.org. uk/\_library/Resources/ICN/Policy\_documents/Calman\_Hine.pdf
- Department of Health, The NHS Cancer Plan: a plan for investment, a plan for reform, September 2000. Available online via: http://webarchive.nationalarchives.gov.uk/+/ www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyandGuidance/DH\_4009609
- Department of Health, Cancer Reform Strategy, December 2007.
   Available online via: http://www.nhs.uk/NHSEngland/NSF/ Documents/Cancer%20Reform%20Strategy.pdf
- Department of Health, Improving Outcomes: a strategy for cancer, January 2011. Available online via: https://www.gov. ul/government/uploads/system/uploads/attachment\_data/ file/213785/dh\_123394.pdf
- Cancer Campaigning Group, Developing excellence in cancer networks, February 2012. Available online via http://www. cancercampaigninggroup.org.uk/wp-content/uploads/2012/02/ Cancer-Networks-report-FINAL.pdf
- Department of Health: Improving Outcomes: A Strategy for Cancer, January 2011. Available online via https://www.gov.uk/government/ uploads/system/uploads/attachment\_data/file/213785/ dh 123394.pdf
- NHS England, Programme Budgeting data, 2012-13, February 2014. Available online via: http://www.networks.nhs.uk/nhsnetworks/health-investment-network/documents/2012-13%20 Benchmarking%20tool\_Published%2021%20Feb%202014.zip
- Cancer Research UK, Cancer incidence for all cancers combined, January 2014. Available online via: http://www.cancerresearchuk. org/cancer-info/cancerstats/incidence/all-cancers-combined/
- Cancer Research UK, Cancer incidence for all cancers combined, January 2014. Available online via: http://www.cancerresearchuk. org/cancer-info/cancerstats/incidence/all-cancers-combined/
- Maddams J et al. 'Cancer prevalence in the United Kingdom: estimates for 2008'. British Journal of Cancer 2009; 101:541-7. Available online via:: http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2720244/
- Cancer Research UK, Cancer incidence by age, January 2014.
   Available online via: http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/age/
- Cancer Research UK, All Cancers (C00-C97), European Age-Standardised Mortality Rates, UK, 1971-2011, April 2013. Available online via: http://www.cancerresearchuk.org/cancer-info/ cancerstats/mortality/all-cancers-combined/
- Cancer Research UK, Cancer statistics: key facts all cancers combined, May 2014. Available online via: http://publications. cancerresearchuk.org/downloads/Product/CS\_KF\_ALLCANCERS.pdf

- Office for National Statistics, Cancer Survival. Available online via: http://www.ons.gov.uk/ons/taxonomy/index. html?nscl=Cancer+Survival
- Office for National Statistics, Cancer Survival. Available online via: http://www.ons.gov.uk/ons/taxonomy/index. html?nscl=Cancer+Survival
- De Angelis, R. et al. (2013), "Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study." Lancet Oncology, 15 (1), pp. 23-34. Available online via: http://www.thelancet.com/%20journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext
- Cancer Research UK, International Cancer Benchmarking Partnership: Module 1: Epidemiology. Available online via http:// www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/ Module-1/
- Cancer Research UK, International Cancer Benchmarking Partnership: Module 1: Epidemiology. Available online via http:// www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/ Module 1/
- Cancer Research UK, International Cancer Benchmarking Partnership: Module 1: Epidemiology. Available online via http:// www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/ Module-1/
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n25/odf/bic2011489a.odf
- 43. World Health Organisation, Cancer prevention. Available online via: http://www.who.int/cancer/prevention/en/
- Cancer Research UK, Statistics on preventable cancer, August 2014. Available online via http://www.cancerresearchuk.org/cancer-info/ cancerstats/causes/preventable/
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- Department of Health, Healthy Lives, Healthy People: A Tobacco Control Plan for England, March 2011. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/213757/dh\_124960.pdf
- Department of Health, Healthy Lives, Healthy People: A Tobacco Control Plan for England, March 2011. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/213757/dh\_124960.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf

## REFERENCES

- Peto, R et al, Mortality from smoking in developed countries 1950-2010. Available online via: http://www.tsu.ox.ac.uk/ research/mega-studies/mortality-from-smoking-in-developedcountries-1950-2010/mortality-from-smoking-in-developedcountries-1950-2010.
- Action on smoking and health, Smoking statistics: who smokes and how much, October 2013. Available online via: http://ash.org.uk/ files/documents/ASH\_106.pdf
- Brown J & West R, 'Smoking prevalence in England is below 20% for the first time in 80 years', British Medical Journal, 2014; 348.
   Available online via: http://www.bmj.com/content/348/bmj.g1378
- Cancer Research UK Cancer statistics: key facts all cancers combined, May 2014. Available online via: http://publications. cancerresearchuk.org/downloads/Product/CS\_KF\_ALLCANCERS.pdf
- Office for National Statistics, Rates of cigarette smoking by sex and age: 1974 to 2012, 2012. Available online via: http://www.ons. gov.uk/ons/rel/ghs/opinions-and-lifestyle-survey/smoking-habitsamongst-adults--2012/rft-smoking-2012.xls
- Department of Health, Health Lives, Healthy People: a tobacco control plan for England, March 2011. Available online via: https:// www.gov.uk/government/publications/the-tobacco-control-planfor-england
- 57. ASH, CRUK and BHF, Beyond smoking kills, October 2008. Available online via: http://www.ash.org.uk/beyondsmokingkills
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- 61. National Obesity Observatory, Child Weight, July 2012. Available online via: http://www.noo.org.uk/uploads/doc/vid\_16006\_ChildWeightFactsheet-July2012.pdf
- Health and Social Care Information Centre, Statistics on obesity, physical activity and diet, February 2014. Available online via: http://www.hscic.gov.uk/catalogue/PUB13648/Obes-phys-acti-diet-eng-2014-rep.pdf
- 63. Public Health England, Child weight data factsheet, August 2014. Available online via: http://www.noo.org.uk/securefiles/140902\_1437//ChildWeight\_Aug2014\_v2.pdf
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n25/pdf/bjc/2011489a.pdf
- Office for National Statistics, Statistical bulletin: Drinking Habits
   Amongst Adults, 2012. Available online via: http://www.ons.gov.uk/
   ons/rel/ghs/opinions-and-lifestyle-survey/drinking-habits-amongst adults-2012/stb-opn-drinking-2012.html?format=hi-vis
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc2011489a.pdf
- Sanderson S et al, 'Awareness of lifestyle risk factors for cancer and heart disease among adults in the UK', Patient education and counselling, 2009:74. Available online via: http://www.ucl.ac.uk/ hbrc/tobacco/pubs/Awareness%200f%20lifestyle%20risk%20 factors 32.pdf

- Office for National Statistics, Statistical bulletin: Drinking Habits Amongst Adults, 2012. http://www.ons.gov.uk/ons/rel/ ghs/opinions-and-lifestyle-survey/drinking-habits-amongstadults-2012/index.html?format=hi-vis
- Dr J Holmes et al., 'Effects of minimum unit pricing for alcohol on different income and socioeconomic groups: a modelling study, The Lancet, 383, pp. 1655-1664, available at: http://image.thelancet. com/journals/lancet/article/PIIS0140-6736(13)62417-4/fulltext
- Cancer Research UK, Malignant Melanoma, European Age-Standardised Incidence Rates per 100,000 Population, by Sex, Great Britain, 1975-2011, April 2014. Available online via: http:// www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/ incidence/uk-skin-cancer-incidence-statistics
- Cancer Research UK, Malignant Melanoma, European Age-Standardised Incidence Rates per 100,000 Population, by Sex, Great Britain, 1975-2011, April 2014. Available online via: http:// www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/ incidence/uk-skin-cancer-incidence-statistics
- Cancer Research UK, Malignant Melanoma, European Age-Standardised Incidence Rates per 100,000 Population, by Sex, Great Britain, 1975-2011, April 2014. Available online via: http:// www.cancerresearchuk.org/cancer-info/cancerstats/types/skin/ incidence/uk-skin-cancer-incidence-statistics
- NHS Choices, Cheap holidays 'increased' melanoma rates, April 2014. Available online via: http://www.nhs.uk/news/2014/04April/ Pages/Cheap-holidays-increased-melanoma-rates.aspx
- Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/264511/105C\_3rd\_Annual\_Report\_-\_Proof\_version\_-9\_ December 2013 v2.0df
- NHS Choices, Cervical cancer vaccine, August 2012. Available online via: http://www.nhs.uk/Conditions/vaccinations/Pages/hpvhuman-papillomavirus-vaccine.aspx
- NHS Choices, Cervical cancer vaccine, August 2012. Available online via: http://www.nhs.uk/Conditions/vaccinations/Pages/hpvhuman-papillomavirus-vaccine.aspx
- Public Health England, Annual HPV vaccine coverage in England 2012 to 2013: by PCT and SHA, December 2013. Available online via: https://www.gov.uk/government/publications/annual-hpv-vaccinecoverage-2012-to-2013-by-pct-and-sha
- British Journal of Cancer, The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010, December 2011. Available online via: http://www.nature.com/bjc/journal/ v105/n2s/pdf/bjc/2011489a.pdf
- Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/gopernment/uploads/system/uploads/attachment\_ data/file/264511/105C\_3rd\_Annual\_Report\_-\_Proof\_version\_-9\_ December\_2013\_v2.pdf
- Public Health England, NHS Cervical Screening Programme.
   Available online via: http://www.cancerscreening.nhs.uk/cervical/about-cervical-screening.html
- 81. Public Health England, NHS Cervical Screening Programme.

  Available online via: http://www.cancerscreening.nhs.uk/cervical/
  about-cervical-screening.html
- NHS Cancer Screening Programmes, HPV triage and test of cure in the cervical screening programme in England. Available here: http://www.cancerscreening.nhs.uk/cervical/hpv-triage-test-ofcure.html Accessed: 27 August 2014

- NHS Cancer Screening Programmes, HPV triage and test of cure in the cervical screening programme in England. Available here: http://www.cancerscreening.nhs.uk/cervical/hpv-triage-lest-ofcure.html Accessed: 27 August 2014
- 84. Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/264511/105C\_3rd\_Annual\_Report\_\_Proof\_version\_-9\_December\_2013\_v2.pdf
- Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/264511/105C\_3rd\_Annual\_Report\_\_Proof\_version\_\_9\_ December\_2013\_v2.pdf
- Public Health England, UK Flexible Sigmoidoscopy Screening Trial. Available online via: http://www.cancerscreening.nhs.uk/bowel/ flexible-sigmoidoscopy-screening-trial.html
- Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/264511/10SC\_3rd\_Annual\_Report\_\_Proof\_version\_-9\_ December\_2013\_V2.pdf
- Public Health England, NHS Breast Screening Programme news and press releases, October 2012. Available online vi: http://www. cancerscreening.nhs.uk/breastscreen/news/041.html
- NHS Choices, Breast cancer (female): screening, July 2012. Available online via: http://www.nhs.uk/Conditions/Cancer-of-the-breastfemale/Pages/Screeningbreastcancer(female).aspx
- Public Health England, NHS Breast Screening Programme news and press releases, October 2012. Available online vi: http://www. cancerscreening.nhs.uk/breastscreen/news/041.html
- 91. Sean Duffy was interviewed by the Cancer Campaigning Group as part of the evidence gathering for this report. Data on file.
- Department of Health, The NHS Cancer Plan: a plan for investment, a plan for reform, September 2000. Available online via: http://webarchive.nationalarchives.gov.uk/+/ www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyandGuidance/DH\_4009609
- 93. Department of Health, Improving Outcomes: a strategy for cancer, January 2011. Available online via: https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/213785/dh\_123394.pdf
- Adapted from The King's Fund and CRUK, How to improve cancer survival, June 2011. Available online here: https://www.kingsfund. org.uk/sites/files/kf/How-to-improve-cancer-survival-Explaining-England-poor-rates-Kings-Fund-June-2011.pdf
- NCIN, Awareness & Early Diagnosis. Available online via: http:// www.ncin.org.uk/cancer\_type\_and\_topic\_specific\_work/ topic\_specific\_work/awareness\_early\_diagnosis
- Public Health England/NCIN, Cancer survival in England by stage. August 2014. Available online via: https://www.gov.uk/ government/news/new-analysis-shows-improving-cancer-survivalin-england-using-world-leading-cancer-staging-data
- Cancer Research UK, Cancer survival for all cancers combined, April 2014, http://www.cancerresearchuk.org/cancer-info/cancerstats/ survival/all-cancers-combined/
- De Angelis, R. et al. (2013), 'Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study.' Lancet Oncology, 15 (1), pp. 23-34. Available online via: http://www.thelancet.com/%20journals/lanonc/article/PIIS1470-2045(13)70546-1/fulltext

- Cancer Research UK, Cancer survival for all cancers combined, April 2014, http://www.cancerresearchuk.org/cancer-info/cancerstats/ survival/all-cancers-combined/
- NCIN, Routes to diagnosis 2006-2010 workbook, March 2014. Available online via: http://www.ncin.org.uk/search/ routes+to+diagnosis
- 101. NCIN, Routes to diagnosis 2006-2010 workbook, March 2014. Available online via: http://www.ncin.org.uk/search/ routes+to+diagnosis
- 102. NCIN, Nearly one in three cancers in elderly are diagnosed as emergency admission to hospital, September 2012. Available online via: http://www.ncin.org.uk/news\_and\_events/routes\_to\_ diagnosis\_press\_release\_september\_2012
- 103. Teenage Cancer Trust (2011), Find Your Sense of Tumour Conference Survey [Data available on request]
- 104. Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/264511/IOSC\_3rd\_Annual\_Report\_\_Proof\_version\_-9\_ December\_2013\_v2.pdf
- 105. NCIN, Urgent GP referral rates for suspected cancer, December 2011. Available online via: http://www.ncin.org.uk/publications/ data\_briefings/gp\_referral\_rates
- 106. NCIN, Urgent GP referral rates for suspected cancer, December 2011. Available online via: http://www.ncin.org.uk/publications/ data\_briefings/gp\_referral\_rates
- 107. NCIN, Urgent GP referral rates for suspected cancer, December 2011. Available online via: http://www.ncin.org.uk/publications/ data\_briefings/gp\_referral\_rates
- Hamilton W, 'Emergency admissions of cancer as a marker of diagnostic delay, British Journal of Cancer, Oct 2012: 107, 1205–1206. Available online via: http://www.nature.com/bjc/ journal/v107/n8/full/bjc2012423a.html
- 109. Cancer Research UK, International Cancer Benchmarking Partnership: Module 12: Population awareness and beliefs. Available online via http://www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/Module-2/
- 110. Cancer Research UK, International Cancer Benchmarking Partnership. Available online via: http://www.cancerresearchuk. org/cancer-info/spotcancerearly/ICBP/
- 111. Cancer Research UK, International Cancer Benchmarking Partnership: Module 12: Population awareness and beliefs. Available online via http://www.cancerresearchuk.org/cancer-info/ spotcancerearly/ICBP/Module-2/
- 112. Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/264511/IOSC\_3rd\_Annual\_Report\_- Proof\_version\_-9\_ December\_2013\_v2.pdf
- 113. Cancer Research UK, Be clear on cancer: lung cancer campaign. Available online via: http://www.cancerresearchuk.org/cancer-info/ spotcancerearly/naedi/beclearoncancer/lung/
- 114. Boughey, A, How can a marketing campaign improve lung cancer survival, December 2013. Available online via: http://scienceblog. cancerresearchuk.org/2013/12/09/how-can-a-marketing-campaignimprove-lung-cancer-survival/
- 115. Cancer Research UK, Be clear on cancer: lung cancer campaign. Available online via: http://www.cancerresearchuk.org/cancer-info/ spotcancerearly/naedi/beclearoncancer/lung/
- 116. Cancer Research UK, Information for GPs: Be Clear on Cancer, October 2012. Available online via: http://www.cancerresearchuk. org/cancer-info/spotcancerearly/naedi/beclearoncancer/ovarian/ Information-for-GPs/

- 117. Department of Health, Improving Outcomes: A Strategy for Cancer Third Annual Report, December 2013. Available online via: https:// www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/264511/IOSC\_3rd\_Annual\_Report\_\_Proof\_version\_-9\_ December\_2013\_vz.pdf
- 118. All Party Parliamentary Group on Cancer, Cancer across the Domains, December 2013. Available online via: http://www. macmillan.org.uk/Documents/Getlinvolved/Campaigns/ Campaigns/APPG/BritainAgainstCancer2013/BritainAgainstCancer-CancerAcrossDomains-reportDec2013.pdf
- 119. Office for National Statistics, Index of cancer survival for Clinical Commissioning Groups in England, December 2013. Available online via: http://www.ons.gov.uk/ons/rel/cancer-unit/a-cancer-survival-index-for-clinical-commissioning-groups/adults-diagnosed-1996-2011-and-followed-up-to-2012/stb---patients-diagnosed-1996-2011.html
- 120. Health and Social Care Information Centre, Clinical Commissioning Group Indicator Portal. Available online via: https://indicators.ir.nbs.uk/webview/
- 121. NHS England, The CCG Assurance Guide 2013/14: operational guidance, November 2014. Available online via: http://www. england.nhs.uk/wp-content/uploads/2013/11/ccg-ass-op-guid.pdf
- 122. John Baron MP was interviewed by the Cancer Campaigning Group as part of the evidence gathering for this report. Data on file.
- 123. Department of Health, Direct Access to Diagnostic Tests for Cancer: Best Practice Referral Pathways for General Practitioners, April 2012. Available online via: https://www.gov.uk/government/uploads/ system/uploads/attachment\_data/file/216503/dh\_133511.pdf
- 124. Cancer Research UK, Cancer survival for all cancers combined, April 2014. Available online via: http://www.cancerresearchuk.org/ cancer-info/cancerstats/survival/all-cancers-combined/
- 125. Macmillan Cancer Support, Multidisciplinary teams. Available online via: http://www.macmillan.org.uk/Cancerinformation/ Cancertreatment/Gettingtreatment/Multidisciplinaryteams.aspx
- 126. Professor Patnick was interviewed by the Cancer Campaigning Group as part of the evidence gathering for this report. Data on file
- 127. NHS England, National Peer Review Programme. Available online via: http://www.nationalpeerreview.nhs.uk/
- 128. Department of Health, The NHS Constitution: the NHS belongs to us all, March 2013. Available online via: http://www.nhs. uk/choiceintheNHS/Rightsandpledges/NHSConstitution/ Documents/2013/the-nhs-constitution-for-england-2013.pdf
- 129. Office of National Statistics and NHS England, Statistics on Waiting Times for Suspected and Diagnosed Cancer Patients Q4 2013-14 Key Points – Provider Based, June 2014. Available online via: http://www.england.nhs.uk/statistics/wp-content/uploads/ sites/2/2014/05/Cancer-Waiting-Times-commentary-Q4-2013-14provider-based-data.pdf
- 130. Office of National Statistics and NHS England, Cancer waiting times press release Q1 2014-14 (provider based), August 2014. Available online via: http://www.england.nhs.uk/statistics/wp-content/ uploads/sites/2/2014/08/CWT-Press-release-2014-15-Q1-Providerbased.pdf
- 131. Office of National Statistics and NHS England, Statistics on Waiting Times for Suspected and Diagnosed Cancer Patients Q4 2013-14 Key Points – Provider Based, June 2014. Available online via: http://www.england.nhs.uk/statistics/wp-content/uploads/ sites/2/2014/05/Cancer-Waiting-Times-commentary-Q4-2013-14provider-based-data.odf

- 132. Office of National Statistics and NHS England, Statistics on Waiting Times for Suspected and Diagnosed Cancer Patients Q4 2013-14 Key Points – Provider Based, June 2014. Available online via: http://www.england.nhs.uk/statistics/wp-content/uploads/ sites/22/2014/05/Cancer-Waiting-Times-commentary-Q4-2013-14provider-based-data.pdf
- 133. Office of National Statistics and NHS England, Cancer waiting times press release Q1 2014-15 (provider based), August 2014. Available online via: http://www.england.nhs.uk/statistics/wp-content/ uploads/sites/2/2014/08/CWT-Press-release-2014-15-Q1-Providerbased.odf
- 134. Cancer Research UK, Putting cancer surgery under the spot light, 2014, May 2014. Available online via: http://scienceblog. cancerresearchuk.org/2014/02/19/putting-cancer-surgery-under-the-spodlight/
- 135. Cancer Research UK, Putting cancer surgery under the spot light, February 2014. Available online via: http://scienceblog. cancerresearchuk.org/2014/02/19/putting-cancer-surgery-under-the-spotlight/
- 136. NHS Choices, Consultant treatment outcomes, June 2013. Available online via: http://www.nhs.uk/choiceinthenhs/yourchoices/ consultant-choice/pages/consultant-data.aspx
- 137. Cancer Research UK, An evaluation of cancer surgery services in the UK, February 2014, available at: https://www.cancerresearchuk.org/ sites/default/files/policy\_cruk\_cancer\_surgery\_services\_feb14.pdf
- 138. NHS England and Cancer Research UK, Vision for Radiotherapy 2014-2024, February 2014. Available online via https://www. cancerresearchuk.org/sites/default/files/policy\_feb2014\_ radiotherapy\_vision2014-2024\_final.pdf
- House of Commons, Hansard, 28 April 2014, c465W. Available online via: http://www.theyworkforyou.com/wrans/?id=2014-04-28d.196472.h
- 140. Cancer Research UK and NHS England, Vision for Radiotherapy, 2014-2014, February 2014. Available online via: http://www. cancerresearchuk.org/sites/default/files/policy\_feb2014\_ radiotherapy\_vision2014-2024\_final.pdf
- 141. Cancer Research UK and NHS England, Vision for Radiotherapy, 2014-2014, February 2014. Available online via: http://www. cancerresearchuk.org/sites/default/files/policy\_feb2014\_ radiotherapy\_vision2014-2024\_final.pdf
- 142. House of Commons, Hansard, 1 September 2014, c140. Available online via: http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm140901/debtext/140901-0004.htm#140901-0004. htm somin1
- 143. House of Commons, Hansard, 1 September 2014, c140. Available online via: http://www.publications.parliament.uk/pa/cm201415/ cmhansrd/cm140901/debtext/140901-0004.htm#140901-0004. htm somin1S
- 144. NHS England, NHS England sets out plan for a sustainable Cancer Drugs Fund, 28 August 2014. Available online via: http://www. england.nhs.uk/2014/08/28/cdf-plan/
- 145. Department of Health, End of Life Care Strategy: promoting high quality care for adults at the end of their life, July 2008. Available online via: https://www.gov.uk/government/uploads/system/ uploads/attachment\_data/file/136431/End\_of\_life\_strategy.pdf
- 146. NICE, Quality standard for end of life care for adults, August 2011. Available online via: http://www.nice.org.uk/guidance/qs13/ chapter/introduction-and-overview
- 147. Public Health England, Electronic Palliative Care Co-ordination Systems in England, April 2014. Available online via: http://www.endoflifecare-intelligence.org.uk/view?rid=787

## REFERENCES

- 148. NHS England, Co-commissioning of primary care services, May 2014. Available online via: http://www.hsj.co.uk/journals/2014/05/12/o/u/ q/2014-05-09-CCG-co-commissioning-letter.pdf
- 149. Cancer Research UK, Measuring Up? The health of NHS Services, September 2014. Available online via: http://www.cancerresearchuk. org/sites/default/files/measuring\_up\_health\_of\_nhs\_cancer\_ services\_sept2014.pdf
- Department of Health, The NHS Outcomes Framework 2014/15, November 2013. Available online via: https://www.gov.uk/ government/publications/nhs-outcomes-framework-2014-to-2015
- 151. Department of Health, Public Health Outcomes Framework 2013 to 2016, June 2014. Available online via:https://www.gov. uk/government/uploads/system/uploads/attachment\_data/ file/263658/2901502\_PHOF\_Improving\_Outcomes\_PT1A\_v1\_1.pdf
- 152. Department of Health, The NHS Outcomes Framework 2014/15, November 2013. Available online via: https://www.gov.uk/ government/publications/nhs-outcomes-framework-2014-to-2015
- 153. Department of Health, Public Health Outcomes Framework 2013 to 2016, June 2014. Available online via: https://www.gov. uk/government/uploads/system/uploads/attachment\_data/ file/263658/2901502\_PHOF\_Improving\_Outcomes\_PT1A\_v1\_1.pdf
- 154. Office for National Statistics, Index of cancer survival for Clinical Commissioning Groups in England, December 2013. Available online via: http://www.ons.gov.uk/ons/rel/cancer-unit/a-cancer-survivalindex-for-clinical-commissioning-groups/adults-diagnosed-1996-2011and-followed-up-to-2012/stb—patients-diagnosed-1996-2011. html
- 155. NHS England, The CCG Assurance Guide 2013/14: operational guidance, November 2014. Available online via: http://www.england. nhs.uk/wp-content/uploads/2013/11/ccg-ass-op-guid.pdf
- 156. Quality Health, National Cancer Patient Experience Survey 2013 National Report, August 2013. Available online via: http://www. quality-health.co.uk/resources/surveys/national-cancer-experiencesurvey/2013-national-cancer-patient-exerience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file
- 157. Macmillan Cancer Support, Key statistics. Available online via: http://www.macmillan.org.uk/Aboutus/Ouresearchandevaluation/ Researchandevaluation/Keystatistics.aspx
- 158. Cancer Research UK, Half of all cancer patients now survive at least 10 years, April 2014. Available online via: http://www.cancerresearchuk. org/about-us/cancer-news/press-release/half-of-all-cancer-patientsnow-survive-at-least-10-years
- 159. Macmillan Cancer Support, Living with or beyond cancer. http://www.macmillan.org.uk/GetInvolved/Campaigns/Weareaforceforchange/ Survivorship/Livingwithorbeyondcancer.aspx
- 160. National Cancer Survivorship Initiative, What is the National Cancer Survivorship Initiative? Available online via: http://www.ncsi.org.uk/ what-we-are-doing/the-recovery-package/
- 161. National Cancer Survivorship Initiative, Living with and beyond cancer: Taking action to improve outcomes, March 2013. Available online via: http://www.ncsi.org.uk/wp-content/uploads/Living-with-andheyond-2013 ndf
- 162. National Cancer Survivorship Initiative, The Recovery Package. Available online via: http://www.ncsi.org.uk/what-we-are-doing/ the-recovery-package/
- 163. National Cancer Survivorship Initiative, The Recovery Package. Available online via: http://www.ncsi.org.uk/what-we-are-doing/ the-recovery-package/
- 164. Mutriem Campbell et al., 'Benefits of supervised group exercise programmes for women being treated for early stage breast cancer: pragmatic randomised controlled trial', British Medical Journal, 2007, 334:517. Available online via: http://www.bmj.com/ content/334/7592/517

- 165. NHS England, Cancer Patient Experience Survey 2013: National Report, August 2013. Available online via: https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-exerience-survey/2013-national-cancer-patient-experience-survey-reports
- 166. NHS England, Cancer Patient Experience Survey 2013: National Report, August 2013. Available online via: http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports
- 167. Macmillan Cancer Support, Cancer Clinical Nurse Specialists: An evidence review, November 2011. Available online via: http:// www.macmillan.org.uk/Documents/AboutUs/Commissioners/ ClinicalNurseSpecialistsAnEvidenceReview2012.pdf
- 168. Macmillan Cancer Support and the National Cancer Action Team, Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist. Available online via: http://www.cancernurse.eu/ documents/NCATMacmillanReportOctober2010.pdf
- 169. Cancer Research UK, Cancer services: reverse, pause or progress? December 2012. Available online via: http://www.cancerresearchuk.org/prod\_consump/groups/cr\_common/@nre/@pol/documents/generalcontent/cruk\_recommendations\_final.pdf
- 170. http://www.cancerresearchuk.org/sites/default/files/measuring\_up\_health\_of\_nhs\_cancer\_services\_sept2014.pdf
- 171. Dr Kennedy was interviewed by the Cancer Campaigning Group as part of the evidence gathering for this report. Data on file.
- 172. BBC News, Big rise in volunteers for medical trials, May 2013. Available online via: http://www.bbc.co.uk/news/health-22594635
- 173. Academy of Medical Sciences, Cancer Research UK, Department of Health and Wellcome Trust, Medical Research: What's It Worth?, 2014. Available online via: http://www.cancerresearchuk.org/sites/ default/files/policy\_june2014\_medical\_research\_whats\_it\_worth\_ briefing\_document.pdf
- 174. National Cancer Research Institute, NCRI Operating Report 2012/13. Available online via: http://www.ncri.org.uk/wp-content/ uploads/2013/10/2013-NCRI-Operating-Report-2012-2013. offnatinershi
- 175. National Cancer Research Institute, NCRI Operating Report 2012/13. Available online via: http://www.ncri.org.uk/wp-content/ uploads/2013/10/2013-NCRI-Operating-Report-2012-2013. ndfnatinershi
- 176. Charities Aid Foundation, UK Giving Report, 2014. Available online via: https://www.cafonline.org/pdf/UK%20Giving%202012-13.pdf
- 177. Cancer Research UK, Pioneering Research 2012-13, 2013. Available online via: http://www.cancerresearchuk.org/prod\_consump/ groups/cr\_common/@fre/@gen/documents/generalcontent/ pioneering-research-12-13.pdf
- 178. Experimental Cancer Medicine Centre Initiative, Impact of the Experimental Cancer Medicine Centre Network 2007-2011, November 2011. Available online via: http://www.ecmcnetwork. org.uk/prod\_consump/groups/cr\_common/@ecm/@gen/ documents/generalcontent/cr 079331.ddf
- 179. UK Trade and Investment, Unlock Your Global Business Potential: UK Stratified Medicine, April 2013. Available online via: https://www. gov.uk/government/uploads/system/uploads/attachment\_data/ file/301775/UK\_Stratified\_Medicine.pdf
- 180. Cancer Research UK, Stratified Medicine Programme. Available online via: http://www.cancerresearchuk.org/funding-forresearchers/hhow-we-deliver-research/our-research-partnerships/ stratified-medicine-programme

- HM Government, Health and Social Care Act 2012, March 2012.
   Available online via: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted
- 182. Academy of Medical Sciences, Cancer Research UK, Department of Health and Wellcome Trust Medical Research: What's It Worth? (2014) http://www.cancerresearchuk.org/sites/default/files/ policy\_june2014\_medical\_research\_whats\_it\_worth\_briefing\_ document.pdf
- 183. Academy of Medical Sciences, Cancer Research UK, Department of Health and Wellcome Trust Medical Research: What's It Worth? (2014) http://www.cancerresearchuk.org/sites/default/files/ policy\_june2014\_medical\_research\_whats\_it\_worth\_briefing\_ document.pdf
- 184. NCRI, Number of cancer patients taking part in clinical studies quadruples in a decade, November 2010. Available online via: http://www.ncri.org.uk/wp-content/uploads/2013/09/NCRI-Press-Release-2010-7Nov.odf
- Cancer Research UK, Our research on clinical trials. Available online via: http://www.cancerresearchuk.org/our-research/our-researchby-cancer-subject/our-research-on-clinical-trials
- 186. Quality Health, National Cancer Patient Experience Survey 2013 National Report, August 2013. Available online via: http://www.quality-health.co.uk/resources/surveys/ national-cancer-experience-survey/2013-national-cancerpatient-exerience-survey/2013-national-cancer-patientexperience-survey-reports/301-2013-national-cancer-patientexperience-survey-programme-national-report/file
- 187. Quality Health, National Cancer Patient Experience Survey 2013 National Report, August 2013. Available online via: http://www.quality-health.co.uk/resources/surveys/ national-cancer-experience-survey/2013-national-cancerpatient-exerience-survey/2013-national-cancer-patientexperience-survey-programme-national-report/file experience-survey-programme-national-report/file
- 188. Quality Health, National Cancer Patient Experience Survey 2013 National Report, August 2013. Available online via: http://www.quality-health.co.uk/resources/surveys/ national-cancer-experience-survey/2013-national-cancerpatient-exerience-survey/2013-national-cancer-patient-experience-survey-proprts/301-2013-national-cancer-patient-experience-survey-programme-national-report/file
- 189. Fern L. et al. 'Available, accessible, aware, appropriate and acceptable: a strategy to improve participation of teenagers and young adults in cancer trials', Lancet Oncology, 2014. Available online via: http://www.thelancet.com/journals/lanonc/article/ PIIS1470-2045(14)70113-5/abstract
- 190. Public Health England/NCIN, Press release: New analysis shows improving cancer sunvival in England using world-leading cancer staging data. August 2014. Available online via: https://www.gov. uk/government/news/new-analysis-shows-improving-cancersunvival-in-england-using-world-leading-cancer-staging-data
- 191. Public Health England/NCIN, Cancer survival in England by stage. August 2014. Available online via: https://www.gov. uk/government/uploads/system/uploads/attachment\_data/ file/347275/Cancer\_survival\_in\_England\_by\_stage\_report\_pdf
- 192. Public Health England/NCIN, Press release: New analysis shows improving cancer survival in England using world-leading cancer staging data. August 2014. Available online via: https://www.gov. uk/government/news/new-analysis-shows-improving-cancersurvival-in-england-using-world-leading-cancer-staging-data
- Chris Carrigan was interviewed by the Cancer Campaigning Group as part of the evidence gathering for this report. Data on file.