ACHIEVING WORLD-CLASS CANCER OUTCOMES

A STRATEGY FOR ENGLAND 2015-2020

Report of the Independent Cancer Taskforce

CONTENTS

EXECUTIVE SUMMARY

Over the next five years, we can improve radically the outcomes that the NHS delivers for people affected by cancer. This report proposes a strategy for achieving this.

It includes a series of initiatives across the patient pathway. These emphasise the importance of earlier diagnosis and of living with and beyond cancer in delivering outcomes that matter to patients. The report recognises that no two patients are the same, either in their cancer or their health and care needs. At its heart, it sets out **a vision for what cancer patients should expect from the health service**: effective prevention (so that people do not get cancer at all if possible); prompt and accurate diagnosis; informed choice and convenient care; access to the best effective treatments with minimal side effects; always knowing what is going on and why; holistic support; and the best possible quality of life, including at the end of life. It is crucial that patients are treated as individuals, with compassion, dignity and respect throughout. The strategy seeks also to harness the energy of patients and communities and encompass their responsibilities to the health service. This means taking personal ownership for preventing illness and managing health; getting involved in the design and optimisation of services; and providing knowledge as experts through experience.

For the NHS, there is the opportunity to **deliver the vision set out in the Five Year Forward View (FYFV)**. Because of the strong evidence base that exists, cancer is uniquely placed to be an early exemplar. Success in delivering the aspirations of this strategy will depend on devolved decision-making, agility, and new models of care, within a framework of national standards and ambitions. In turn, this will be reliant on research and intelligent use of data to drive continuous improvement, as well as a "test and learn" approach in areas where the evidence of what works is immature. It will also be reliant on the culture and attitude of health care professionals in embracing partnership working with patients, seeing them as equals in decisions about their treatment and care.

Over the last ten years, we have been able to fill critical gaps in our knowledge about cancer. We have begun to understand its intricacies better as well as the short and long term impacts it can have on patients. This has enhanced our ability to address these impacts and deliver improved outcomes for patients, their carers and their families, as well as limit the burden that cancer places on society.

However, the number of people diagnosed and living with cancer each year will continue to grow rapidly, even with major improvements in prevention. The primary reasons for this are our ageing population and our success in increasing survival. This will place significant additional demand on health and social care services. Cancer survival in England has improved significantly over the last 15 years. More than half of people receiving a cancer diagnosis will now live ten years or more. But our mortality rates are higher than they could be. In addition, unacceptable variability exists in access to and experience of care across different areas, sub-groups of the population and cancer types. There is much we could do to improve patient experience and long-term quality of life, and to make our care more patient-centred.

The Independent Cancer Taskforce has consulted widely to determine how the NHS can deliver a step-change in outcomes. It has identified where opportunities exist for improvement, and how resources can be used differently and in a more targeted way. Realising the potential will require a broad set of approaches, including more integrated pathways of care and increased investment. It will need the active involvement of a range of individuals and organisations beyond the NHS. Many of these approaches will deliver benefits not just for cancer patients, but for people with a range of other conditions. They will also deliver financial savings in the medium to long term.

This report encompasses a large number of recommendations. However, we propose that the six strategic priorities over the next five years should be:

- **Spearhead a radical upgrade in prevention and public health:** The NHS should work with Government to drive improvements in public health, including a new tobacco control strategy within the next 12 months, and a national action plan on obesity. We should aim to reduce adult smoking prevalence to less than 13% by 2020 and less than 5% by 2035;

- **Drive a national ambition to achieve earlier diagnosis:** This will require a shift towards faster and less restrictive investigative testing, quickly responding to patients who present with symptoms, by ruling out cancer or other serious disease. We recommend setting an ambition that by 2020, 95% of patients referred for testing by a GP are definitively diagnosed with cancer, or cancer is excluded, and the result communicated to the patient, within four weeks. Delivering this will require a significant increase in diagnostic capacity, giving GPs direct access to key investigative tests, and the testing of new models which could reduce the burden and expectation on GPs;

- **Establish patient experience as being on a par with clinical effectiveness and safety:** We have the opportunity to revolutionise the way we communicate with and the information we provide to cancer patients, using digital technologies. From the point of cancer diagnosis onwards, we recommend giving all consenting patients online access to all test results and other communications involving secondary or tertiary care providers by 2020. We should also systematise patients having access to a Clinical Nurse Specialist (CNS) or other key worker to help coordinate their care. We should continue to drive improvement through meaningful patient experience metrics, including the annual Cancer Patient Experience Survey, which should be embedded in accountability mechanisms;

- **Transform our approach to support people living with and beyond cancer:** We recommend accelerating the roll-out of stratified follow up pathways and the "Recovery Package". The aim should be that by 2020 every person with cancer will have access to elements of the Recovery Package, and stratified pathways of follow-up care will be in place for the common cancers. A national quality of life measure should be developed by 2017 to ensure that we monitor and learn lessons to support people better in living well after treatment has ended. We also recommend that CCGs should commission appropriate End of Life care, in accordance with the NICE quality standard, and taking into account the independent Choice Review and forthcoming Ambitions;

- **Make the necessary investments required to deliver a modern high-quality service, including:**

  - Implementing a rolling plan to replace linear accelerators (linacs) as they reach 10-year life and to upgrade existing linacs when they reach 5-6 years;
  - Working to define and implement a sustainable solution for access to new cancer treatments, building from the Cancer Drugs Fund;
  - Rolling out a molecular diagnostics service which is nationally-commissioned and regionally delivered, enabling more personalised prevention, screening and treatment;
  - Implementing plans to address critical workforce deficits and undertaking a strategic review of future workforce needs and skills mix for cancer. The priority deficit areas to address should be radiology, radiography and endoscopy for diagnosis; and clinical oncology, medical oncology and clinical nurse specialists for treatment and care;
  - Supporting a broad portfolio of cancer research.

- **Overhaul processes for commissioning, accountability and provision.** We recommend setting clearer expectations, by the end of 2015, for how cancer services should be commissioned. For example, most treatment would be commissioned at population sizes above CCG level. By 2016, we should establish Cancer Alliances across the country, bringing together key partners at a sub-regional level, including commissioners, providers and patients. These Alliances should drive and support improvement and integrate care pathways, using a dashboard of key metrics to understand

variation and support service redesign. We should also pilot new models of care and commissioning. For example, the entire cancer pathway in at least one area should have a fully devolved budget over multiple years, based on achieving a pre-specified set of outcomes.

The National Audit Office has estimated cancer services cost the NHS approximately £6.7bn per annum in 2012/13. The Five Year Forward View projections indicate that this will grow by about 9% a year, implying a total of £13bn by 2020/21. The recommendations set out in this report will cost an estimated £400m per annum, of which approximately £300m per annum may already be included within the FYFV baseline projections. However, in the medium term, implementation of these recommendations should contribute substantially in excess of £400m per annum to the projected £22bn funding gap.

If the NHS is successful in implementing the initiatives and ambitions outlined in this strategy, we expect that the most significant benefits will be:

- An additional 30,000 patients per year surviving cancer for ten years or more by 2020, of which almost 11,000 will be through earlier diagnosis;
- A closing of the gap in survival rates between England and the best countries in Europe and elsewhere;
- Better integration of health and social care such that all aspects of patients' care are addressed, particularly at key transition points;
- Cancer patients feeling better informed, and more involved and empowered in decisions around their care;
- A radical improvement in experience and quality of life for the majority of patients, including at the end of life;
- A reduction of the growth in the number of people being diagnosed with cancer;
- A reduction in the variability of access to optimal diagnosis and treatment and the resulting inequalities in outcomes;
- Significant savings which can be re-invested to cope with increases in demand and to achieve further improvements in outcomes.

1. THE CURRENT LANDSCAPE OF CANCER IN ENGLAND

Every two minutes someone in England will be told they have cancer. Half of people born since 1960 will be diagnosed with cancer in their lifetime[1] (see Figure 1), with that proportion continuing to rise. The good news is that cancer survival is at its highest ever[2], with significant improvements made over the last 15 years. More than half of people receiving a cancer diagnosis will now live ten years or more[i2]. This progress has been driven by improvements in our knowledge of how to treat and control cancer, combined with the commitment of NHS staff to deliver transformative care.

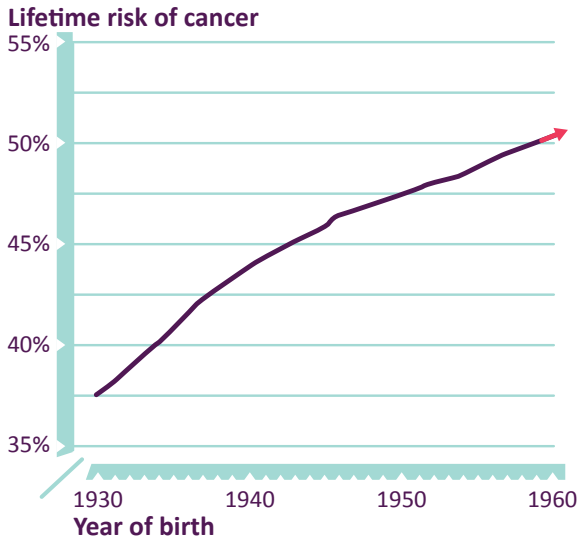


Figure 1: Lifetime risk of cancer[1]

A total of 280,000 individuals are now diagnosed with cancer in a year, a number which has been growing by around 2% per annum[3] (see Figure 2). Around half of these diagnoses will be of the most common cancers – breast, lung, prostate, and colorectal – and the other half will be of rare or less common types. Incidence is expected to reach over 300,000 diagnoses in 2020, and more than 360,000 in 2030[4]. The rise is due partly to the ageing and growth of the population, a result of the overall success of the healthcare system, such that people are less likely to die early from other conditions, such as cardiovascular disease. But the rise in cancer diagnoses is also in part driven by shifts in our lifestyles, which are increasing our age-standardised risk. These changes place increasing demands on the health system, alongside demands resulting from the changing nature of other conditions. As noted in the FYFV, long-term health conditions – rather than illnesses amenable to a one-off cure – now consume 70% of the health service budget.

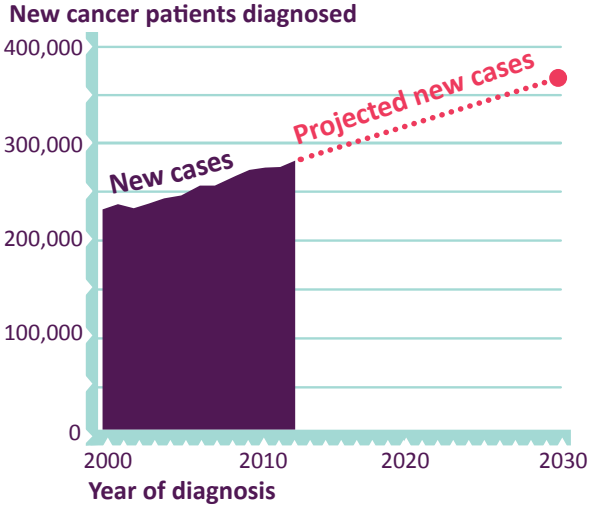


Figure 2: Incidence projection[4]

Cancer is the biggest cause of death from illness or disease in every age group, from the very youngest children through to old age, with mortality significantly higher in men than in women. Death rates in England have fallen by more than a fifth over the last 30 years and by 10 per cent over the last decade[5]. They are expected to continue to fall, with a drop of around 17% by 2030[6] (see Figure 3). But 130,000 people still die from cancer each year – a number that has remained relatively constant as incidence has increased. There also remain groups of patients for whom outcomes and quality of life are particularly poor. Survival has improved significantly in some types of cancer, notably malignant melanoma, breast, testicular and prostate cancers. However, in lung, pancreas and oesophageal cancers and most brain tumours, survival has remained stubbornly low to date.

[i]Age-standardised ten-year survival from all cancers is now above 50%

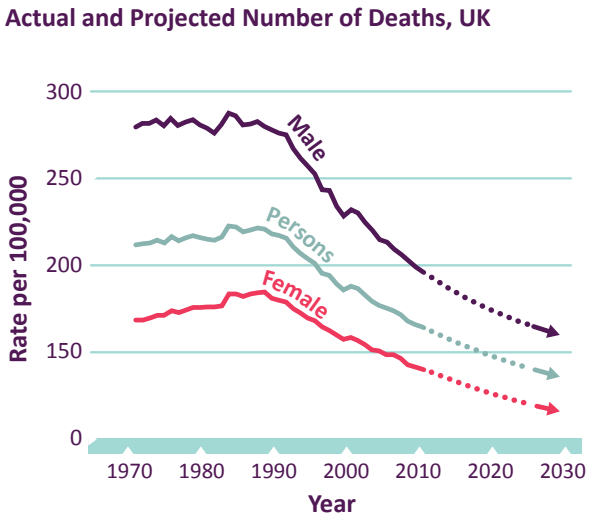


Figure 3: Cancer mortality projections – actual and projected number of deaths, persons, UK[6]

We see significant variation in survival outcomes for patients across England. For example, one year survival in some CCGs is more than 10% higher than in others[7]. This variability cannot be explained solely by correlation with deprivation levels. It can be quantified across a number of indicators. For example, there is around a two-fold difference in the proportion of cancers diagnosed at an early stage[8].

Health inequalities across England mean there is potentially avoidable variation in survival outcomes[9] (see Figure 4). There would be around 15,300 fewer cases and 19,200 fewer deaths per year across all cancers combined[9] if socio-economically deprived groups had the same incidence rates as the least deprived . More than half of the inequity in overall life expectancy between social classes is linked to higher smoking rates among poorer people.

The combination of improvements in survival and detection, and a growing and ageing population has resulted in an estimated 2 million people living in England who have had a cancer diagnosis. This represents an increase of 0.3 million in the last five years[10] and the number is projected to rise to 3.4 million in 2030[10] (see Figure 5). Of people living with cancer, prostate is the most prevalent type in men and breast in women.

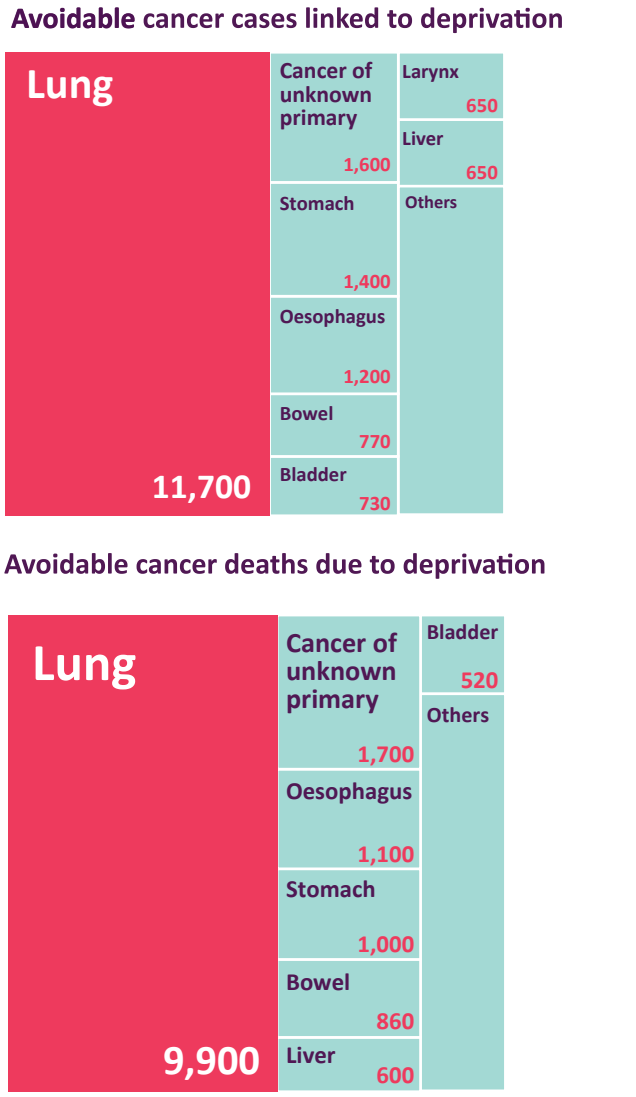


Figure 4: Yearly excess cancer cases and deaths attributed to deprivation[9]

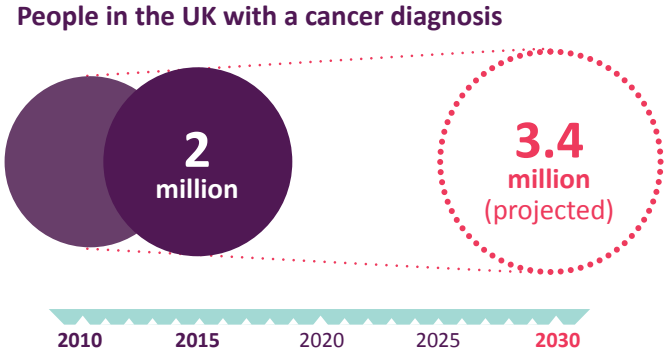


Figure 5: Projections of cancer prevalence in England, 2010 – 2030[10]

Patient experience of hospital treatment has been measured systematically for the last four years and been positive overall. However, this masks considerable variability, with older and younger patients, those from BME groups, those with less common

cancers and those in some parts of the country such as London all reporting lower levels of satisfaction[11]. Furthermore, patients across the country report that poor communication is the aspect of care most in need of improvement, both in terms of the information they are given about their diagnosis and treatment options, and in the level of compassion and empathy they receive.

Historically, there has been less focus on the care received by patients after their initial treatment. We know that patients who have been diagnosed with cancer have a greater risk of being diagnosed with cancer again in the future. Many of the treatments we use can have long-term physical and mental health consequences, which result in a high proportion of individuals requiring subsequent health and social care support, and there are also practical impacts for patients such as loss of income. Our lack of attention to these issues may result in poorer quality of life for patients and increased pressure on their carers, as well as inefficient use of scarce resources.

Many patients treated for a primary cancer will also develop secondary or metastatic cancer, which can often be incurable. Nevertheless, these patients may live for many years with the disease, and they should be given the treatment and support they need to live for as long and as well as possible, managing their cancer effectively as a chronic condition.
The experience and quality of life that patients have through and beyond diagnosis and treatment is equally as important as clinical effectiveness and safety. Because the majority of cancer patients are over the age of 65, it is also the case that many have multiple morbidities. It is estimated that 70% of cancer patients have at least one other long-term condition that needs managing and over a quarter have at least three other such conditions[12] (see Figure 6).

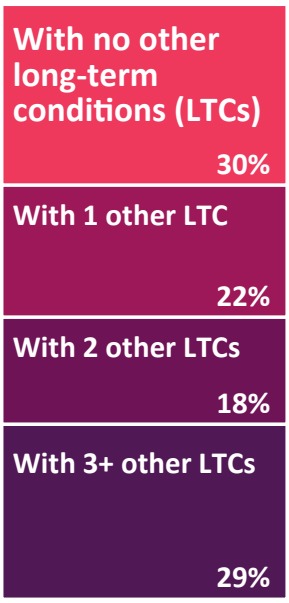


Figure 6: Proportion of people with cancer in the UK living with other long-term conditions[12]

Many patients have inadequate care support or may be carers themselves. Therefore, it is imperative to take a holistic and individual perspective in considering the after-treatment care and support that patients need. Not doing so can have multiple adverse consequences, not least exacerbating the "bed-blocking" problem which bedevils NHS secondary care services.

For too many people, cancer remains a disease from which they will die. Evidence shows that many of these people are not experiencing the care they would like at the end of their lives. Around three in four people with cancer would prefer to die at home with the right support and with their friends and family around them, rather than in a hospital or hospice[13]. However, less than a third are able to exercise that choice at present. We also know that just one in five people with cancer who die at home have complete pain relief all the time in the last three months of life, compared with just under two-thirds of those with cancer who die in a hospice[14].

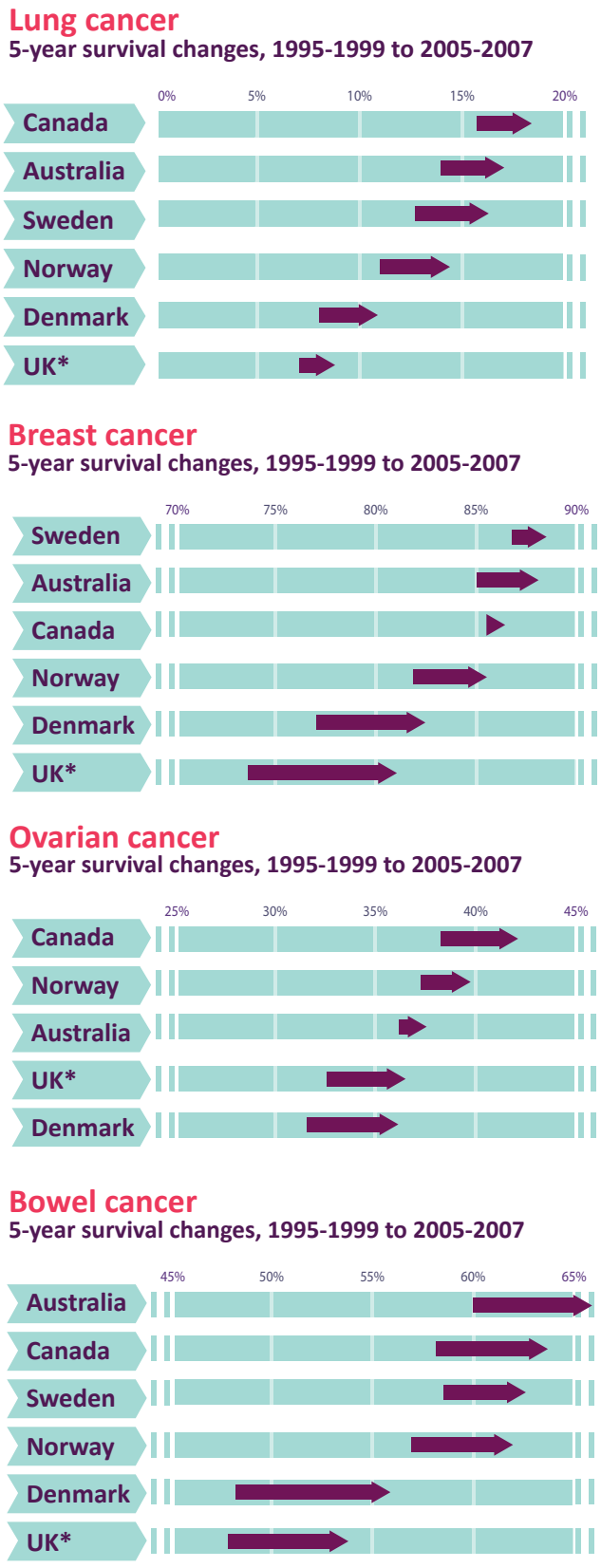
Despite international surveys[15] ranking the NHS highly on the basis of overall performance in health and efficiency, this is not true of cancer outcomes, in which we lag considerably behind countries of similar wealth. Some aspects of our delivery – such as screening and vaccine uptake, and smoking cessation services – are admired across the world, but this is not reflected in

our survival rates. We have amongst the lowest levels of cancer incidence of rich countries, but amongst the highest levels of mortality[16]. This situation has persisted since researchers began collating these data systematically in the 1990s. There is now strong evidence that late diagnosis and sub-optimal access to treatment – particularly for patients with more advanced disease - are the key drivers for these poorer clinical outcomes.[17-21]

The most up-to-date published international comparisons[ii] show that relative survival during 1995-2007 improved for breast, colorectal, lung and ovarian cancer patients in all jurisdictions[22]. However, the gap in survival between the highest performing countries (Australia, Canada and Sweden) and the lowest (England, Northern Ireland, Wales and Denmark) remains largely unchanged, except for breast cancer, where the UK is narrowing the gap[22] (see Figure 7). More recently, the survival gap has also started to close in stomach and rectal cancers, according to as yet unpublished data. But it remains significant in lung and colon cancers. Here there is also evidence of a worse stage distribution at diagnosis than comparator countries, i.e. cancers are more advanced on average at the time of diagnosis.

Treatment differences play a more significant role than anticipated at the time these international comparisons were initiated, with survival within stage being poorer in England too (particularly for more advanced breast and ovarian cancers). Across Europe, cancer survival for older people (75 and above) tails off markedly compared with survival for younger age groups (e.g. 55-64)[23]. In 2012, one year survival was 57% and 77% in these groups respectively[23].

Over the last several years, the growth in demand for cancer services has not been met by an associated growth in capacity. There are significant workforce deficits, particularly in diagnostic services, oncology, and in specialist nursing support. These shortfalls result in severe bottlenecks in the diagnostic process, suboptimal care in certain parts of the country, and an inability to deliver newer, evidence-based and cost-effective treatments. Neither do we have the optimal capacity and configuration of resources to support patients beyond their initial treatment.



* UK includes England, Northern Ireland and Wales

Figure 7: Age standardised five-year survival trends, 1995 – 2007, by cancer and country[22]

[ii]Comparisons are with countries that also have universal health coverage and comprehensive cancer registration

Finally, commissioning of cancer services has become highly fragmented and, partly as a result, insufficiently accountable. CCGs consistently report that they have neither the expertise nor the time adequately to commission complex cancer services, many of which are changing rapidly as research drives progress. Until recently, CCGs had little role in the commissioning of diagnostic services, and some still do not. Pathways are neither optimised for patients nor for use of resources. Furthermore, there is a lack of hard accountability when providers or commissioners fail to meet national targets, as demonstrated by hospitals missing the 62-day wait standard for over a year[24].

In conclusion, there may be much to celebrate since the first NHS Cancer Plan was published in 2000, but there remains much more to do.

2. AMBITIONS AND PERFORMANCE METRICS

This strategy focuses on the outcomes which matter most to patients and society. This is not only about improving survival. We also need to ensure that we reduce the incidence of cancer and improve patients' experience and quality of life.

2.1 CANCER INCIDENCE

Much could be done to slow the rise in the numbers of patients being diagnosed with cancer each year. Increasing incidence places a considerable burden on the NHS. But it also places a huge burden on patients and their families, as they undergo intensive and sometimes debilitating treatment. We recommend focusing attention on two key ambitions in this area:

- **We will start to see a discernible fall in age-standardised incidence and a reduction in the number of cases linked to deprivation.** As noted above, overall incidence has been rising, and we have also seen an increase (5%) in age-standardised incidence rates over the last ten years. Prevention efforts take time to feed through in to incidence, beyond a five-year timeframe, but setting an ambition that is measured and reported on will keep the focus on these efforts, so that we see the benefits in the longer term.

- **By 2020, adult smoking rates will have fallen much further.** Smoking remains by far the largest modifiable risk factor for cancer, responsible for around 60,000 new cases per year in England[25].This strategy sets a specific ambition that adult smoking rates should fall to 13% by 2020, and that rates in routine and manual workers should fall to 21%.

2.2 CANCER SURVIVAL

Achieving improvements in survival will require a combination of earlier detection and diagnosis, better treatment and access to treatment, improved access to data and intelligence and reductions in variability around the country. Some cancer types, e.g. some less common cancers or those with the poorest outlook, will offer greater scope for gains than others. This strategy focuses on three ambitions related to survival:

- **Increase in 5 and 10-year survival.** Surviving for ten years following a cancer diagnosis is far more meaningful for patients than one or five years. Many experts believe it should be possible that, by 2034, 3 in 4 patients in England diagnosed with cancer will survive at least 10 years following their diagnosis, compared with 50% now, benefitting around 150,000 patients per year. By 2020, 57% of patients should be surviving ten years or more.

- **Increase in one-year survival, with a reduction in CCG variation.** Surviving one year after diagnosis is clearly a pre-requisite for long term survival and data is available much sooner, which enables commissioners and providers to track progress. Furthermore, one-year survival trends, alongside staging data, will specifically enable us to assess progress on earlier diagnosis. We propose that one-year survival should reach 75% by 2020 for all cancers combined, compared with 69% now. Reducing variability will be a key driver of overall improvement at a population level. Whilst it is implausible that variability can be eliminated entirely, raising survival across CCGs towards the highest levels being delivered today should be possible.

- **Reduction in survival deficit for older people.** Recent international comparison data suggests that the deficit in survival is even greater for older people than it is for younger age groups for some types of cancer. Moreover, if we are to narrow the gap with other countries overall, we will also need to do so with older patients.

2.3 PATIENT EXPERIENCE AND QUALITY OF LIFE

The NHS needs to move to a more patient-centred service in line with the aspirations set out in the FYFV, with a change in the relationship between patients and professionals. It is therefore appropriate to have ambitions that reflect this shift. In addition, we need to transform our approach towards supporting people to live well outside hospital and to return to their lives as far as possible after treatment has ended. To achieve this requires a significant focus on measuring and improving people's quality of life. For some areas, we do not yet have reliable measures, so these will need to be developed over the coming years:

- **Continuous improvement in patient experience with a reduction in variation.** In the latest Cancer Patient Experience Survey (CPES), 89% of patients said overall their care was excellent or very good[11]. It is quite likely that patient expectations will increase in coming years, so that maintaining or improving on this level of satisfaction will require considerable effort. Some patient groups, such as those with rare and less common cancers, report less satisfactory experience. In addition, some areas of the country score poorly on patient satisfaction measures and we should expect these areas to deliver significant improvement in the coming years. CPES should continue to evolve and should be repeated every year, with patient satisfaction measured for every hospital and CCG.

- **Continuous improvement in long-term quality of life.** We want people with cancer to lead healthy, fulfilled and productive lives, as far as is possible, whether they have completed treatment or are living with an advanced and incurable form of the disease. To this end the strategy proposes the development of a national metric of quality of life, underpinned by a robust approach to measurement, which will incentivise the provision of better aftercare interventions, as well as more informed choice at the point of diagnosis.

2.4 UNDERPINNING METRICS

Many of the metrics proposed above are only available after a considerable time lag. Therefore it is essential that we also have a series of supporting metrics, which will enable commissioners and providers to have more rapid feedback on the impact of interventions and more timely intelligence on the likely trajectory against the ambitions set out above. These metrics should also be a key focus for Cancer Alliances, as the main vehicles for local service improvement (see section 8.2).

Recommendation 1: NHS England, working with the other Arms Length Bodies, should develop a cancer dashboard of metrics at the CCG and provider level, to be reported and reviewed regularly by Cancer Alliances. The following metrics should be included as a minimum:

CCG Dashboard:

- **Proportion of patients referred by a GP with symptoms receiving a definitive cancer diagnosis or cancer excluded within 2 and 4 weeks, with a target of 50% at 2 weeks and 95% at 4 weeks by 2020**

- **Proportion of diagnoses through emergency presentation**

- **Proportion of cancers diagnosed at stage 1 or 2, with a target of 62% by 2020 for cancers staged, and an increase in the proportion of cancers staged**

- **Screening uptake, with an ambition of 75% for FIT in the bowel screening programme by 2020**

- **One-year survival**

- **Proportion of patients meeting cancer waiting times targets: target of 96% meeting 31 day target and 85% meeting 62 day target**

- **CPES data**

- **Proportion of patients with patient-agreed written after-treatment plan, with a target of 95% by 2020**

- **Under-75 mortality**
- **Over-75 indicator (to be developed)**
- **Further patient experience and quality of life measures as they are developed, e.g. Patient Reported Outcome Measures (PROMs)**
- **Proportion of people who die who had a personalised end of life care plan**

Provider Dashboard:

- **Proportion of patients meeting cancer waiting times targets: target of 96% meeting 31 day target and 85% meeting 62 day target**
- **CPES data**
- **Data from clinical audits**
- **Further patient experience and quality of life measures as they are developed, e.g. PROMs**
- **Proportion of cancer patients participating in research**

Figure 8 is an illustration of how the 'cancer dashboard' for a CCG might be presented, including many of the metrics above. Where data are available we would expect them to be broken down across different cancer types and equality groups on request. The dashboard would be generated by the National Cancer Intelligence Network in conjunction with NHS England.

For people who die from cancer, we need to incentivise the system to ensure these individuals experience a "good" death, with their preferences taken in to account. A good deal of end of life care is provided outside the NHS and suitable metrics have been proposed in the Choice Review.

Cancer performance in Exampleshire CCG

Cancer Taskforce

June 2015

Introductory notes about this CCG, the measures included and the data sources, including sources for further information and any important notes, caveats or points to consider.

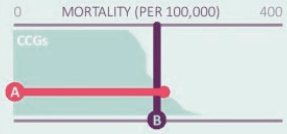
KEY

Better than England average | Similar to England average | Worse than England average | Meets official target | Does not meet official target

Differences are statistically significant based on 95% confidence levels

VITAL STATISTICS EXAMPLESHIRE CCG

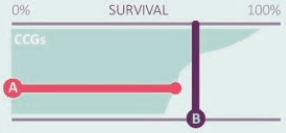
Mortality (under-75s)



A This CCG B England average

Mortality rates per 100,000 in people aged under 75.

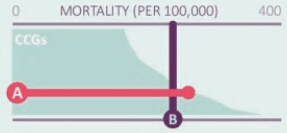
Survival (one-year)



A This CCG B England average

% of people surviving their cancer for one year or more.

Mortality (over-75s)

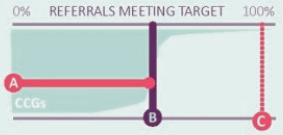


A This CCG B England average

Mortality rates per 100,000 in people aged under 75.

EARLY DIAGNOSIS EXAMPLESHIRE CCG

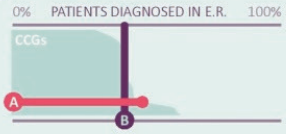
Referrals complete in 2-4 weeks



A This CCG B England average C Official target by 2020

% of patients referred by a GP receiving cancer diagnosis or cancer excluded within 4 weeks.

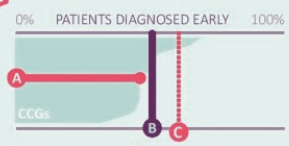
Emergency presentation



A This CCG B England average

% of cancer patients diagnosed through emergency presentation.

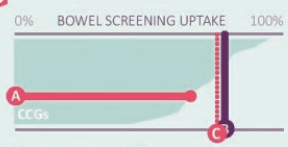
Diagnoses at early stage



A This CCG B England average C Official target

% of cancer patients diagnosed at stages 1 and 2.

Screening uptake



A This CCG B England average C Official target

% of eligible people receiving bowel screening.

CANCER SERVICES EXAMPLESHIRE CCG

31 & 62 day waiting times

A This CCG B England average C Official target

% of patients meeting cancer waiting times targets (31 and 62-day measures).

After-treatment patient plans

A This CCG B England average C Official target

% of patients with patient-agreed written after-treatment plan.

PATIENT EXPERIENCE PROVIDER NAME

Overall care rating analysis

Strong positive ratings across all Cancer Patient Experience Survey measures.

Quality of life analysis

Good Patient Recorded Outcomes Measures, with room for improvement in communications.

Quality assessment

Good quality assessment results, with room for improvement in four aspects of training.

Clinical audit analysis

Poor clinical audit performance, especially in standards of outpatient care.

Figure 8: Example 'dashboard' of metrics

3. PRINCIPLES

Certain principles are central to the context and successful implementation of this strategy:

- **One-size fits no-one:** No two patients are the same, either in their cancer or in their needs. We must strive towards greater stratification and personalisation of approaches. Critical to this will be systems and processes which capture the needs and circumstances of individual patients and their carers, and the recognition and acceptance by doctors and other health care professionals of the patient as an equal partner in their care.

- **Co-design:** It is clear that fragmentation of care is a reality for patients across many health and social care pathways. Putting the patient at the heart of the re-design of services for cancer (and other long-term conditions) will require a will and determination that must be realised. This principle should be embedded in every aspect of the cancer journey, to ensure that services are responsive to patients' needs.

- **Pre- and post- treatment are as important as treatment:** This strategy places considerable emphasis on the prevention and earlier diagnosis of cancer, as well as on living with and beyond cancer, and end-of-life care.

- **Individual responsibility and self-management:** We need to facilitate and empower people to take their share of responsibility for staying healthy and where appropriate enable them to manage their health and care needs.

- **Devolved decision-making, within national standards and ambitions:** Cancer services (and the NHS more broadly) are too extensive for all decisions to be made nationally. Local or regional decision-making unlocks creativity and innovation, provides a vehicle for clinicians and patients to drive service development, and enables appropriate consideration of local circumstances (e.g. rural geographies). However, local decision-making must be within a national framework of agreed service quality standards and appropriate population sizes.

- **Systems of external accountability:** Many different organisations at local and national level deliver services to prevent cancer and to treat and support cancer patients. Individual care pathways can span several of these organisations. A system of external accountability is therefore necessary, both at local and national levels, to ensure cross-organisational issues are appropriately considered and resolved.

- **Research and data as drivers of continuous improvement:** Substantial opportunities exist to reduce variation and to drive progress through intelligence and innovation. All parts of the health service must embed a culture in which data and intelligence are seen as drivers of improvement and that research and controlled data access are viewed as a core responsibility.

- **Agility:** The pace of progress in all aspects of cancer means that we need processes and systems that are agile and adaptable. Agility will enable the rapid spread of cost-effective innovations. Furthermore, this strategy takes a "test and learn" approach in many areas, recognising that we don't know all the answers to the many different challenges we face, and we need to try different solutions and evaluate them carefully before national roll-out.

- **Cancer as an exemplar for other conditions:** Many aspects of cancer services are relevant for other conditions. Equally, a large proportion of cancer patients have one or more other long-term conditions. Cancer is uniquely placed to drive forward the vision set out in the FYFV. We should learn what works for cancer, and ensure we apply lessons as quickly as possible to other areas. Cancer care should also take opportunities to learn from other conditions.

4. HOW SHOULD WE REDUCE THE GROWTH IN THE NUMBER OF CANCER CASES?

Chapter Summary

- More than 4 in 10 cases of cancer are caused by aspects of our lifestyles which we have the ability to change. Tobacco remains the main risk factor, followed by obesity
- We need to continue to raise awareness of the impact risk factors have on our health, especially in selected populations, and support people to make changes
- Efforts to tackle smoking rates should continue at pace, with the ultimate aim of reaching 5% in adults by 2035
- Vaccination and chemo-prevention will play an increasing role
- With increasing numbers of people surviving their primary cancer, we need a stronger focus on preventing secondary cancers

There is much more we could do to ensure that people are engaging with health and community services early enough to shift focus onto preventing rather than treating disease. The ability of our National Health Service to deliver the care required now and in the future is entirely dependent on the health of our nation. We will not be able to sustain comprehensive health and social care coverage unless we take more concerted action on prevention. Rising numbers of cancer cases that could be prevented should be seen as unacceptable. It is within our control to prevent many cases of cancer and we should seize this opportunity. This will require fundamentally resetting the social contract within society, such that individuals take more responsibility for their own health. It will also require stronger leadership from Government, healthcare providers, and local organisations, so that individuals are supported in making appropriate lifestyle choices. This is important not only for cancer but a variety of other potentially avoidable conditions such as cardiovascular disease, diabetes and dementia.

The figures for England are stark. Despite being widely acknowledged as having the best smoking cessation services in the world, nearly one in five adults still smokes. A third of people drink too much alcohol. A third of men and half of women don't get enough exercise. Almost two thirds of adults are overweight or obese. Our young people have the highest consumption of sugary soft drinks in Europe[26].

4.1 LIFESTYLE AND AWARENESS

An estimated 4 in 10 cases of cancer could be prevented, largely through modifying aspects of our lifestyles which we have the ability to change[27]. The main risk factors include tobacco, weight, diet, alcohol consumption, UV exposure and lack of sufficient physical activity (see Figure 9). These are supplemented by other exposures, such as air pollution, occupational risks, infections (including Human Papilloma Virus and viral hepatitis B and C) and radiation.

Awareness needs to start early. The progression of children through school presents an opportunity to influence lifestyle behaviours, including through children being able to influence their families. Information on healthy lifestyles could be packaged with more tailored content relating to common signs and symptoms of cancer and other conditions. Early awareness would also provide young people with the confidence to make best use of primary care services in later life, for example in how to have constructive conversations about their health.

Figure 9: Preventable cancer risk factors

Subject to evaluation of pilots being undertaken by Teenage Cancer Trust and others, NHS England and Public Health England should consider the evidence base for rolling out a cancer education programme to all secondary schools to raise awareness of healthy lifestyles and cancer symptoms.

The health of the nation is not solely the responsibility of NHS organisations; we need to harness efforts across local government, employers and the wider community to tackle prevention. Many local approaches are already in place or are being developed. However, there is now a need for greater urgency, with concerted action to focus on cancer. Local organisations are best-placed to determine which combination of initiatives across education, housing, planning and healthcare would deliver the most impact, and which should be led through workplace health and wellbeing initiatives. A local approach also enables occupational risk factors in specific geographies to be taken into account. It is important to note that most risk factors are relevant to a number of different illnesses and diseases. Increased risk of cancer can be a powerful driver of change for many individuals, but there are low levels of awareness of the links between many risk factors and cancer.

Health and Wellbeing Boards (HWBs) can continue to play a valuable role as facilitators to encourage local government, local health services, communities and charities to work together to develop local strategies, taking a cross-disease approach, to address major social and environmental determinants of ill health. An important part of local strategies will be health promotion initiatives to raise awareness and help individuals make healthier choices around risk factors including smoking, alcohol, diet and physical activity. Partners should work together to ensure that local approaches are tailored to the local community, and appropriately target specific groups in which certain cancer types are particularly prominent (e.g. prostate cancer, triple-negative breast cancer for BME groups).

Each time a person interacts with the health service is an opportunity to encourage a conversation about healthy lifestyles. Making 'every contact count' is an essential culture shift that needs to be embraced by everyone in the NHS who has contact with the public and has the opportunity to have a conversation to improve health.

4.2 SMOKING

Smoking rates have halved in Great Britain over the last 35 years, declining steadily since the 1970s (see Figure 10). Current rates for all adults in England are at 18.4%[28] although rates vary by age. This remarkable change is principally down to governments adopting a comprehensive and consistent approach, both in supporting smokers to quit and in discouraging and denormalising smoking in society as a whole. Indeed, we have not yet seen the benefit of measures introduced in the last Parliament, some of which are still to be implemented.

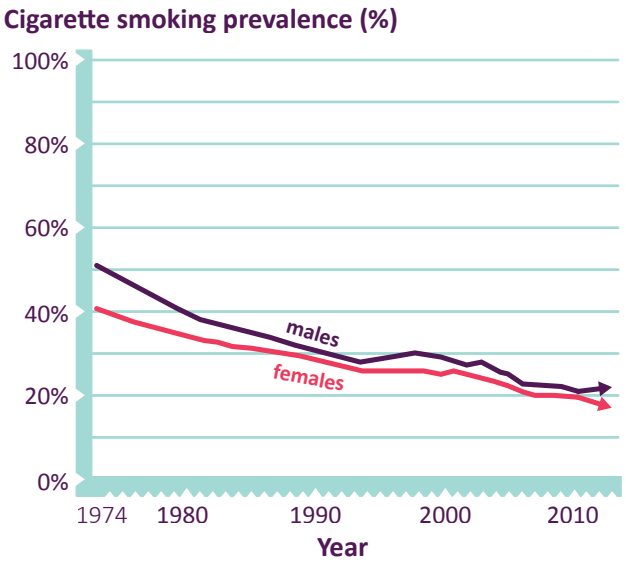


Figure 10: Cigarette smoking prevalence (%), Great Britain[29]

But smoking still kills. 18.4% of the population equates to more than 8m adults; up to two-thirds of long term smokers will die as a result of their smoking if they do not quit[30]. Smoking remains the leading cause of preventable death and disease in England, responsible for around one in six deaths of adults aged 35 and over in 2013[31]. It remains the largest preventable cause of cancer, with an estimated 19% of cancer cases and more than a quarter of cancer deaths in the UK linked to exposure to tobacco smoke[25, 32]. Around 60,000 cases per year could be prevented if tobacco smoke exposure was eliminated[25]. There is growing evidence that smoking not only impacts cancer risk but also response to treatment. There is also a strong financial rationale to continue to tackle smoking. The estimated total cost of tobacco use to society in England is £13.8 billion per year[33], compared with revenue from tobacco in 2013/14 of £7.6 billion[34].

Smoking throws into sharp focus the challenge we face in England to tackle health inequalities. Smoking prevalence is higher amongst people with lower incomes (23% of individuals in the lowest income band, compared to just 11% amongst those who earn £40,000 or more[29]). In addition, smoking is relatively widespread amongst people with mental health problems; an estimated 42% of tobacco in England is used by people with mental health issues[35]. Smoking related inequalities also exist by gender, sexual orientation, and level of education.

It is imperative that we maintain a focus to drive down smoking rates further and target those groups with the worst outcomes to reduce health inequalities. For hard to reach groups, evidence suggests that smoking cessation services and taxation are the interventions which make the biggest difference. High quality smoking cessation services, coupled with Government action on marketing and taxation, mean that we should be optimistic that further declines are possible in the years ahead. New technologies such as e-cigarettes offer additional means to help people quit. Public Health England and Government should carefully monitor the research programme initiated by Cancer Research UK, in conjunction with PHE, to understand better the use and safety of e-cigarettes in reducing tobacco consumption.

Adult smoking rates have been declining by around 0.7% per year over the last 10 years[29]. If we maintain the current trajectory, we would therefore be at 15% by 2020. We recommend being more ambitious than this. The Government's existing tobacco control plan comes to an end in 2015. A recent report by ASH sets out some of the steps we should consider next[36].

Recommendation 2: Government should work with Public Health England and NHS England to publish a new tobacco control plan within the next 12 months. The ambition should be to reduce adult smoking prevalence to less than 13% by 2020 and less than 5% by 2035, and reduce smoking among routine and manual workers to 21% by 2020. The plan should include a full range of actions, such as a tobacco industry levy, a tax escalator, payment based incentives to ensure smoking cessation services are strengthened and a focus on groups where smoking rates remain high, including social marketing campaigns where appropriate. It should highlight the importance of NHS action in primary and secondary care, in particular among those with long-term conditions.

4.3 OBESITY AND OVERWEIGHT

Obesity represents a critical challenge to the NHS, and its impact on the health of our nation is growing in significance. England is

amongst the worst performers on obesity in Western Europe. The proportion of the population that is overweight increased from 58 per cent to 67 per cent in men and from 49 per cent to 57 per cent in women between 1993 and 2013[37] (see Figure 11). Sixteen per cent of boys and 15% of girls aged 2 to 15 are obese[37]. The proportion of children who are obese doubles while they are at primary school. Less than one in ten are obese when they enter reception class, but by the time they reach year six, nearly one in five are obese. A programme of work should be undertaken to evaluate the curriculum in primary schools and how lifestyle factors and behavioural changes are communicated.

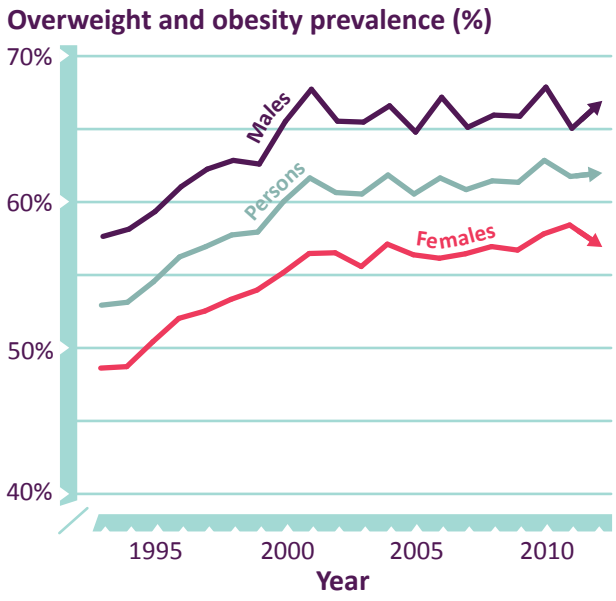


Figure 11: Obesity and overweight prevalence (%), England

These statistics presage significant problems for the future in the form of cancer and other illnesses. An estimated 5% of cancer cases in the UK each year are linked to excess bodyweight - 17,000 cases a year across bowel, womb, oesophageal, pancreatic, kidney, liver, gallbladder and post-menopausal breast cancers[38] – as well as being linked to other conditions such as diabetes. Obesity can also have an impact on survival once a person has developed cancer because certain 'life-saving' treatments, including surgery, may not be available to patients. Unlike tobacco, there has to date not been coordinated and concerted action taken to address obesity, and it is essential that this now becomes a priority.

Recommendation 3: Public Health England should work with the Government and a wide range of other stakeholders to develop and deliver a national action plan to address obesity, including a focus on sugar reduction, food marketing, fiscal measures and local weight management services. Within this there should be a strong focus on children. Implementation of the programme should be supported by PHE, aligned with the physical activity strategy 'Everybody active, every day'.

4.4 ALCOHOL

Alcohol consumption has more than doubled in the UK since the 1950s[39, 40]. Excessive alcohol consumption leads to around 12,800 UK cases of cancer each year and is linked to several different types of cancer[41]. As little as one standard drink a day can increase the risk of a number of cancers. Consumption clearly has wide-reaching impacts beyond cancer, including increasing the risk of other health conditions, and to date much of the focus has been on these wider societal issues. Awareness amongst the public of the links between alcohol and cancer specifically is low, with only a third identifying it as a risk factor. Therefore there is an opportunity for a comprehensive alcohol strategy to acknowledge the risk of cancer to help drive behaviour change. PHE has undertaken a rapid evidence review of alcohol harm and prevention and is writing a report to Government which will outline possible policy solutions.

Recommendation 4: The PHE report should form the basis for the development of a national strategy to address alcohol consumption, possibly including measures to tackle price, marketing, availability, information on products and social marketing campaigns to raise awareness.

4.5 UV RADIATION EXPOSURE

UV exposure is linked to one frequently lethal cancer, malignant melanoma, which is increasing in incidence. It is now the fifth most common cancer type in England, responsible for 1,900 deaths per year[42]. Continued action on UV exposure therefore

remains important to prevent more cases of this cancer. There are a number of simple actions that individuals can take to reduce their exposure to UV radiation, but where certain populations continue to need support is in making healthy choices related to sunbeds. In those areas where sunbed use remains high, local strategies can helpfully include measures to limit over-exposure to UV radiation. Health and Wellbeing Boards provide a forum to bring together local partners to ensure, through the joint Strategic Needs Assessment (JSNA) process, that strategies are tailored to the needs of the local community and are appropriately targeted to high-risk groups.

4.6 HPV INFECTION

HPV is one of the most common sexually transmitted infections. Persistent infection with high-risk HPV types can lead to the development of cervical, other rare ano-genital cancers and some cancers of the head and neck.

The HPV vaccine is currently offered routinely to females aged 12 to 13 years and the programme's primary aim is to reduce the incidence of cervical cancer in women. The HPV vaccination programme in England has been one of the most successful in the world, with more than 86% of year 8 girls receiving all three doses[43] and early indications of a reduction in HPV 16/18 infections[43]. Since September 2014, the programme has switched to a two-dose schedule. The success of this programme needs to be sustained and built upon. Men who have sex with men are a group at high risk for HPV infection, and will benefit much less from the herd protection effects of the adolescent female programme. Expanding the vaccination programme to include this group of men is under consideration currently by the Joint Committee of Vaccination and Immunisation (JCVI). Assessment of the extension of HPV vaccination to adolescent boys is ongoing and as the benefits of HPV vaccination become better known, there is good reason to consider the effectiveness and cost-effectiveness of gender-neutral vaccination.

Recommendation 5: By December 2016, PHE should determine the level at which HPV vaccination for boys would be cost-effective. JCVI should make a final decision by 2017. Assuming a cost-effective price can be achieved, national roll-out should take place by 2020.

4.7 DRUGS TO PREVENT CANCER

The use of drugs to prevent cancer (including secondary cancers) is increasingly likely to play a key role, particularly to prevent breast cancers in specific groups of women. Tamoxifen is indicated for five years for pre-menopausal women at high risk and either tamoxifen or aromatase inhibitors, e.g. anastrazole, for post-menopausal women at high risk, e.g. those who have a strong family history[iii][44]. However, there is currently considerable variability in uptake and adherence of these medicines, given the long period over which they are taken. A more systematic approach to making these drugs available could significantly improve outcomes.

Recommendation 6: NHS England should work through CCGs to ensure that GPs are appropriately prescribing chemo-preventive agents to reduce the risk of invasive breast cancer where their use is established through NICE guidelines.

Approximately 5% of colorectal cancers have a genetic hereditary basis[45]. Some patients with these cancers have hereditary non-polyposis colorectal cancer (HNPCC) or Lynch Syndrome. A randomised controlled trial has shown that the long term use of daily aspirin by individuals known to harbour these genetic mutations can substantially reduce the incidence of subsequent colorectal cancer[46].

Recommendation 7: NHS England should commission NICE to develop updated guidelines for the use of drugs for the prevention of breast and colorectal cancers. Updated guidelines should consider the use of aromatase inhibitors for untreated post-menopausal women at high risk and the use of aspirin for individuals with HNPCC. Once these guidelines are published, CCGs should

[iii]Use of tamoxifen or an aromatase inhibitor for five years in post-menopausal women at high risk has been shown to reduce the risk of invasive breast cancer by 50% or more, with the benefit extending to 20 years or more

ensure that GPs appropriately implement them.

Cancer Research UK and the National Institute for Health Research (NIHR) will continue to monitor outcomes from trials under way in the UK and internationally regarding the role of aspirin in cancer prevention more generally. They will make evidence available to NHS England and NICE as results become clear.

4.8 LIFESTYLE-BASED SECONDARY PREVENTION

With an increasing number of patients surviving their primary cancers, there is a growing need for the health service to tailor preventative approaches to reduce the chance of secondary cancer (metastasis). Many of the risk factors that increase the chance of a primary cancer also increase the risk of cancer spreading. Patients can take action to reduce this risk. There is strong evidence for physical activity. Regular exercise has been shown through multiple observational studies[iv] to reduce the risk of a number of different types of secondary cancer by 10-50% and also to reduce the risk of cancer-specific death[47]. The majority of the evidence is in early breast cancer, but there is also evidence in early colorectal, prostate and ovarian cancers. Advice on weight control, exercise, limiting alcohol consumption and reducing smoking rates should be given to all patients to reduce their risk of secondary cancer.

Research has shown that people who have had cancer would like more information about how to approach lifestyle changes. They would also welcome support tailored to their individual needs[48]. A study which focused on people who had survived bowel cancer found that many participants had actively sought advice to improve their lifestyle, but had been confused by mixed messages and a lack of confidence from health professionals who gave advice[49].

Recommendation 8: NHS providers should ensure that all patients treated for cancer are given advice, tailored to their individual circumstances and risk level, on how to improve their lifestyle. This advice should include healthy eating, weight control, physical activity levels, smoking cessation and alcohol consumption, to help prevent secondary cancers. This advice should be recorded in their medical notes.

Recommendation 9: NHS England should ask NIHR and research charities to undertake research to improve understanding of who experiences secondary cancer and recurrence, and to evaluate the benefit of rehabilitation and exercise programmes post-treatment in secondary prevention.

4.9 OCCUPATIONAL EXPOSURES

Exposures to cancer causing agents in the workplace are the fifth most important contributor to preventable cancer cases in Great Britain after tobacco, diet, obesity and alcohol[27]. Current estimates show that about 5% of cancer deaths and 4% of cancer cases each year are due to workplace exposures that have occurred in the past[50]. The Health and Safety Executive (HSE) has a list of prioritised cancer causing agents in today's workplaces around which it focuses its activity to reduce exposure. HSE's interventions are tailored for each cancer-causing agent and industry of concern, and include working with stakeholders to support them to raise awareness and encourage behavioural change and. Using their inspection and enforcement capability, HSE is able to focus on poor-performing businesses. This work needs to continue.

[iv] Although not yet in large prospective randomised studies

5. HOW SHOULD WE IMPROVE SURVIVAL?

Chapter Summary

- There is a substantial opportunity to diagnose many more cancers earlier, which would lead to better patient outcomes
- Cancer screening will continue to evolve, with the bowel programme needing particular attention
- We need to shift behaviours so that GPs are encouraged to refer for tests at a lower threshold of suspicion of cancer, and try new approaches for patients to access tests
- We will have to invest to increase our diagnostic capacity. Otherwise, the system will be unable to cope with current requirements, let alone increased demand
- Patients should have access to the best evidence-based treatments available. This will mean reducing variation across the country, upgrading our radiotherapy technology, and using medicines in more stratified ways
- Certain groups of patients will need a targeted focus to improve care. These include older people; children, teenagers and young adults; and people with serious mental illnesses and learning difficulties
- The NHS must support a broad portfolio of cancer research to improve continually the care we provide to patients

5.1 SCREENING

The national cancer screening programmes are for large groups of the population, most of whom have no symptoms of cancer, looking for early signs that cancer is developing or already present. Screening contributes to reducing incidence and improving outcomes for those patients whose cancers can be treated at an earlier stage. England's existing cancer screening programmes already save thousands of lives. However, ongoing research shows there is the potential to do better, both through improving screening uptake and introducing new tests where applicable.

Population-based cancer screening currently detects around 5% of all cancer cases, including around 30% of breast cancers and 10% of bowel cancers[51]. The breast screening programme saves around 1,300 lives per year in the UK. But it also results in around three women being over-diagnosed for every life saved. This means cancers are detected and treated that would not have gone on to cause any problem for the women concerned within their lifetimes[52]. As yet, there is no reliable way to distinguish aggressive cancers and therefore determine which cancers require treatment. But research is ongoing to address this, particularly into ductal carcinoma in situ (DCIS).

The bowel and cervical screening programmes also act as prevention programmes, through the detection and removal of pre-cancerous lesions that might have gone on to become cancer subsequently. Both programmes save thousands of lives per year.

In England, there is considerable variation in uptake of screening for the three existing programmes. This variation results in health inequalities. For example, 50% more BME women of screening age (12%) than white women (8%) say they have never attended a cervical screening appointment[53]. Uptake is also often worse in communities of lower socio-economic status.

The UK National Screening Committee (NSC) has commissioned an evidence review into best practice to increase uptake, which will report by the end of 2015. Recommendations will then be developed into programme standards. PHE should turn these into key performance indicators for quality assurance (QA) teams and Cancer Alliances

to assess local programmes.

Of the three existing screening programmes, bowel and cervical will undergo significant changes in the next five years due to changes in technology, while changes to the breast screening programme are currently subject to trials.

5.1.1 Bowel cancer screening

The NHS Bowel Cancer Screening Programme (BCSP) has been running since 2006. Regular bowel cancer screening has been shown to reduce the risk of dying from bowel cancer by 16% in the population invited[54]. There are two aspects to the bowel screening programme – the original guaiac Faecal Occult Blood test (gFOBt), offered every two years for men and women aged 60 to 74 in England, and the new complementary bowel scope screening programme for 55-year olds, which is currently being rolled out.

In 2014/15, overall uptake for gFOBt bowel screening was around 58%, with wide variation across the country (33 – 67 per cent)[v]. The geographical variation, and the range of uptake across different groups, demonstrates a significant opportunity to improve.

One way to improve uptake is replacement of the gFOBt test with the more sensitive and easier-to-use faecal immunochemical test (FIT). Positive findings from the FIT pilot have indicated improved uptake of screening in both sexes and across all quintiles of the index of multiple deprivation, with notable improvements in the most deprived quintile[55]. Introduction of the FIT test is therefore likely to increase demand on already stretched endoscopy services due to this improved uptake and also because FIT is a more sensitive test. As FIT is quantitative, the appropriate threshold for a positive test needs to be set. Until such time as endoscopy capacity improves, roll-out plans should consider the potential for risk stratification or whether thresholds should start high and reduce over time.

Research has shown that for every 190 people screened, bowel scope stops one person from getting bowel cancer, and for every 490 people screened, saves one life from bowel cancer[56]. Adenomas and polyps can be removed during the procedure, which reduces the chances of these developing into bowel cancer in the future. Bowel scope roll-out has been slower than anticipated and needs to continue at pace. This will require current workforce deficits to be addressed (see section 8.5.2).

Recommendation 10: Assuming a positive recommendation by the NSC, PHE and NHS England should roll out FIT into the BCSP, replacing gFOBt as soon as possible. NHS England should incentivise GPs to take responsibility for driving increased uptake of FIT and bowel scope in their populations, with an ambition of achieving 75% uptake in all CCGs by 2020.

5.1.2 Cervical screening

Cervical screening using the Papanicolaou (Pap) test has been around since the 1940s, but it was not until the NHS call and recall system was introduced in 1988 that England started to see major falls in the incidence and mortality of cervical cancer.

As at March 2014, 72 per cent of eligible women in England aged 25 to 49 had undergone cervical screening in the last three and a half years. 77 per cent of eligible women in England aged 50 to 64 had been screened in the last 5 years, down from a high of 81 per cent in 2004/05[57]. Experts estimate that cervical screening saves around 5,000 lives each year in the UK[58]. Cervical screening currently uses liquid-based cytology. Recent evidence suggests that using human papilloma virus (HPV) as the primary test would mean that women would not need to attend as often for cervical screening and that more cases of cancer would be prevented. This therefore has cost-saving potential for the NHS, as well as being an opportunity to improve outcomes.

Recommendation 11: Assuming a positive recommendation by the NSC, PHE and NHS England should drive rapid roll-out of primary HPV testing into the cervical screening programme, with an aim of commencing roll-out by 2016 and full

[v]Data are taken from the National BCSP reporting system, not yet publically available

national coverage by 2020. The NSC should also regularly review whether the upper age limit for cervical screening remains appropriate.

5.1.3 Breast cancer screening

The NHS Breast Screening Programme (BSP) has been running in England since 1988. In 2013-14, uptake of breast screening in women aged 50 -70 was 72 per cent, compared with 75 per cent in 2003-04[59]. A trial is currently underway examining whether to extend the screening age range to between 47 and 73 and will report after 2020. Research is also needed to examine the impact of the addition of tomosynthesis to mammography in the BSP, for the 1 in 3 women with dense breast tissue, where mammography can miss some cancers.

5.1.4 Screening leadership

Timely implementation of screening from trial, to pilot, to full roll-out requires coordination, workforce planning and resource management between Public Health England and those who commission and deliver the service within the NHS. Furthermore, there is a myriad of local initiatives designed to improve coverage and uptake. It is essential that these initiatives are evaluated and that lessons are collated and shared. Leadership of the national screening programmes, including robust quality assurance, is therefore essential, especially in the context of a programme which straddles Public Health England and NHS England. This leadership also needs to oversee regular updates to public information.

Recommendation 12: A new cancer screening team under the Director of Screening within PHE should include a lead for all current and future cancer screening programmes. This should be matched with designated screening leadership in NHS England, with the responsibility of ensuring accountability and quality, and driving improvements and implementation of new services.

5.1.5 New screening programmes

Evidence relating to possible new screening interventions is constantly evolving as new tests are developed and clinical studies are undertaken. Results on mortality from the UK Collaborative Trial of Ovarian Cancer Screening are due at the end of 2015, and results from a number of lung cancer screening studies in high risk people (smokers and ex-smokers) are due in 2016.

Recommendation 13: The NSC should examine the evidence for lung and ovarian cancer screening. PHE should be ready to pilot lung or ovarian screening within 12 months of a significant positive mortality outcome and cost-effectiveness evidence from studies currently under way, together with a plan for subsequent national roll-out.

There is currently no organised screening programme for prostate cancer. The Prostate Cancer Risk Management Programme was introduced with a primary care information pack in 2002. This informed choice scheme enables men to decide whether or not to have the prostate specific antigen (PSA) test based on the available evidence about risks and benefits. The NSC review of prostate cancer screening is due to complete by the end of 2015, and will make recommendations on whether further action needs to be taken.

5.1.6 Risk-based approaches to screening

Inherited genetic mutations can now identify the 0.7% of women who have a three-fold increased risk of breast (i.e. to a 1 in 3 risk)[60] and the 1% of men with a six-fold increased risk of prostate cancer (i.e. to a 1 in 2 risk)[61], compared to the rest of the population. We need to evaluate how we could incorporate this knowledge into programmes that can support individuals in prevention and/or active surveillance, as well as providing appropriate genetic counselling, given the potential implications for family members. Any developments would ideally work in conjunction with existing screening programmes. This area is discussed further in section 5.4.1.

Recommendation 14: NHS England and Public Health England should work with NIHR and research charities to develop research protocols to evaluate the potential for risk-based prevention and surveillance programmes based on germline genetic profiling.

5.2 EARLY DIAGNOSIS

Diagnosing substantially more cancers earlier could be transformative in terms of improving survival reducing mortality and improving quality of life. Earlier diagnosis makes it more likely that patients will receive treatments such as surgery and radiotherapy which contribute to the majority of cases where cancer is cured.

When bowel cancer is diagnosed at the earliest stage, more than 9 out of 10 people survive at least 10 years (see Figure 12). However, if diagnosed at late stage survival is below 5%; fewer than 1 in 10 people are currently diagnosed at the earliest stage[62]. When lung cancer is diagnosed at the earliest stage, more than 8 in 10 people survive for at least a year, but less than 2 in 10 people are diagnosed at the earliest stage[63]. This picture is mirrored in many other types of cancer. Cancer Research UK has estimated that there would be a 0.5% increase in 10-year cancer survival for every 1% increase in the proportion of patients diagnosed at the earliest stages (1 or 2), for all cancers combined.

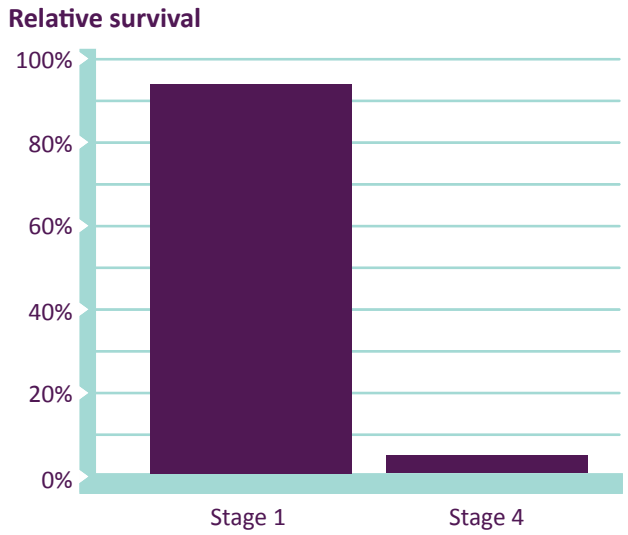


Figure 12: Bowel cancer ten-year relative survival by stage at diagnosis

In the period 2006-2010, over a fifth of newly diagnosed cancer patients in England received their diagnosis as a result of an emergency presentation[51]. Often these patients have cancers which are at an advanced stage[64], meaning these cancers are less amenable to curative treatment, and therefore have significantly poorer survival than those diagnosed through other routes (see Figure 13). For example, women are four times less likely to have surgery if breast cancer is diagnosed through an emergency presentation than if it is diagnosed through an urgent referral[65].

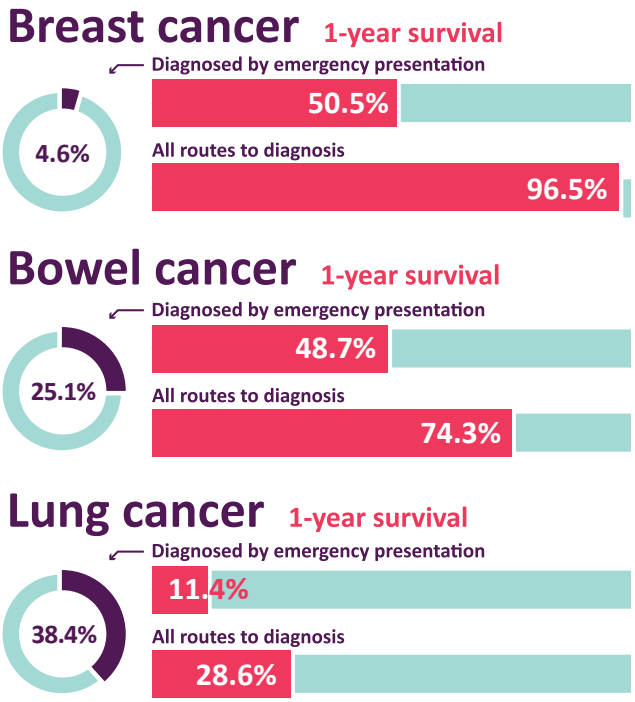


Figure 13: Proportion of diagnoses and impact on one-year survival by emergency presentation[51]

The proportion of cancers diagnosed following an emergency presentation varies considerably across the country, from 15 per cent in some CCGs to 37 per cent (see Figure 14). The proportion of emergency diagnoses also varies between cancer types and by age – patients under 25 and over 75 are the most likely to present as emergencies, as are patients with less common cancers[51]. A socio-economic gradient is also observed, with more affluent patients being less likely to present as emergencies.

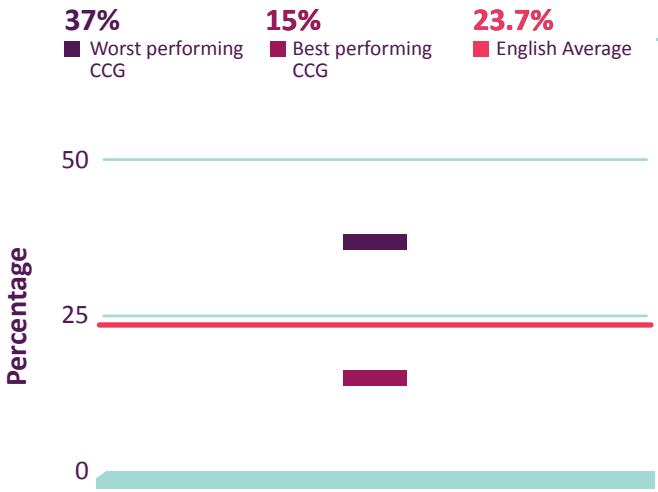


Figure 14: Proportion of patients diagnosed via an emergency presentation[vi]

Variation in the stage at which cancers are diagnosed exists between geographic locations, ethnicities, genders and across socio-demographic factors. It is estimated that thousands of advanced stage diagnoses could be avoided each year if socio-demographic inequalities at stage of diagnosis were eliminated[66].

England continues to have lower cancer survival than comparable countries, i.e. those of similar wealth with universal health coverage, such as Sweden, Australia and Canada[22]. Late diagnosis is one of the major reasons explaining our poorer outcomes. There is evidence that we are beginning to close the survival gap in breast cancer, but the gap remains significant in colon, rectal and lung cancers[67]. We have a particularly poor stage distribution at diagnosis for lung and bowel cancers compared to the best performing countries.

Some CCG populations have one-year survival outcomes for some types of cancer close to some of the best-performing countries, indicating that pathways to diagnosis are working well, but nowhere does this include all the types of cancer studied. Across England, there is around a two-fold variation in the proportion of cancers diagnosed at an early stage, suggesting significant scope for improvement[8] (see Figure 15).

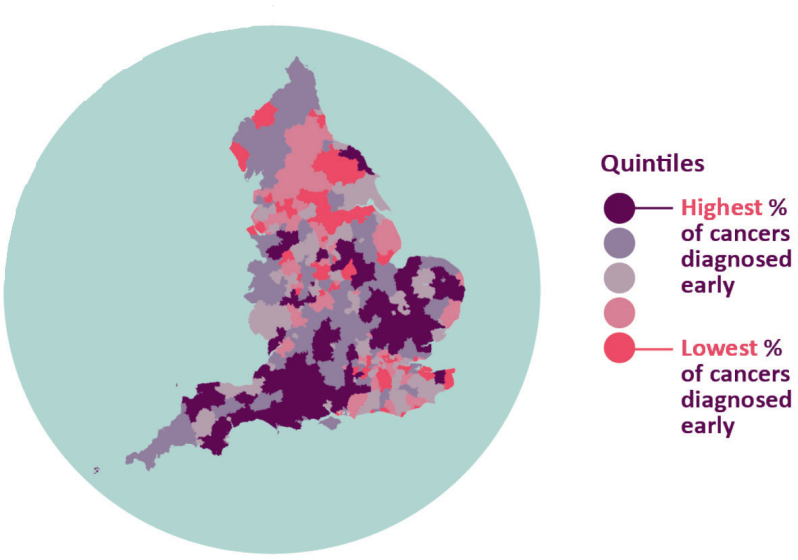


Figure 15: Stage of diagnosis, by local authority, 2012[8]

Delays in diagnosis and treatment can lead to avoidable deaths. They can also cause considerable anxiety for patients and carers and increased morbidity. Treating late stage patients is also very costly and almost always more expensive than treating patients with early stage

[vi]Number of patients diagnosed in 2008 with cancer through emergency presentation as a proportion of patients diagnosed through all routes. Data from NCIN, charts generated by Cancer Research UK

disease. For example, an early stage colon cancer patient would incur approximately £3,400 in NHS treatment costs on average, whereas a late stage patient would incur £12,500[68]. Cancer Research UK has recently estimated that if all areas of England achieved a stage distribution at diagnosis comparable with the best, this would save the NHS around £44m a year in treatment costs for breast, bowel, lung and ovarian cancers, as well as saving many more lives[68]. In practice, this will be an underestimate, since there is also an opportunity across most other types of cancer and for the best to get considerably better.

Late diagnosis is a multifaceted problem. The National Awareness and Early Diagnosis Initiative was launched in 2008[vii] and has led to coordinated investment in research, data collection, analysis, policy activity and a range of interventions[69, 70].

5.2.1 Public awareness

International survey data suggest that people in England are as aware of key cancer symptoms as those in other countries. Many hold generally positive beliefs about cancer, believing that 'cancer can often be cured'[71]. But people in the UK are significantly more worried and embarrassed than those in other countries about seeing their doctor with a symptom that might be serious – 'worried about wasting the doctor's time' being the main endorsed statement[71]. They also report greater difficulty in getting an appointment with a GP as a barrier to presentation[71].

Awareness campaigns which focus on the need to present if a set of symptoms exists are therefore a very useful approach in encouraging the public to see their GP quickly, as is primary care capacity[viii]. Be Clear on Cancer is a set of social marketing campaigns, run by Public Health England in partnership with the Department of Health and NHS England and supported by Cancer Research UK. The brand has been used to promote symptom awareness and early diagnosis of eight different cancer types, as well as a more generic campaign which focused on four key signs of many types of cancer. All of these campaigns have been carefully evaluated, with the majority delivering positive results in encouraging earlier presentation. Evaluation of the national lung campaign run in 2012 showed that an estimated 700 additional lung cancers were diagnosed during that period than the same period the previous year. Approximately 400 more people had their cancers diagnosed at an earlier stage and around 300 additional patients had surgery, a treatment that is inappropriate once lung cancers are more advanced[72]. The campaigns have also helped educate the public that many cancers are treatable if caught early and have helped to change attitudes amongst some GPs.

Recommendation 15: Public Health England should continue to invest in "Be Clear on Cancer" campaigns to raise awareness of possible symptoms of cancer and encourage earlier presentation to health services. Campaigns should include lung, breast over 70s, and other cancer types where pilots prove effective. PHE should also explore the use of this brand to improve uptake of screening programmes, particularly amongst disadvantaged groups. NHS England, Public Health England and the Department of Health should jointly plan campaigns to ensure an integrated roll-out across the service, with a minimum of two national campaigns each year.

5.2.2 GP referral

GPs in England see fewer than eight new cancer cases per year on average[ix], but many more patients present with symptoms which could be cancer. GPs are required to evaluate these symptoms and determine whether to refer for an investigative test which might then lead to a definitive diagnosis. In almost all types of cancer, definitive diagnosis is only possible through a biopsy examined by a pathologist. This is usually only undertaken after a range of blood, imaging or endoscopy tests.

A GP can refer patients for a test through an urgent referral (two-week wait) pathway if

[vii] NAEDI is co-chaired with Cancer Research UK
[viii] GP capacity is addressed in section 5.2.5
[ix] Calculated by the Statistical Information Team at Cancer Research UK using 2011 UK cancer incidence and NHS workforce data on the total number of GPs in the UK in 2011

they strongly suspect cancer. Greater use of this pathway has been shown to be linked with reduced mortality[73]. However, only 27% of cancers are diagnosed through this route[51]. The proportion of patients referred through the urgent pathway who are subsequently diagnosed with cancer is around 10%. This "threshold of suspicion" is much higher than in many other countries.

Danish studies and the International Cancer Benchmarking Partnership have shown that healthcare systems with a "gatekeeping" role (i.e. UK and Denmark) have significantly lower one year cancer survival than systems without such gatekeeper functions. The role of GPs in the early diagnosis of cancer is extremely challenging given there are more than 200 different types of cancer and many have vague symptoms. But it is also pivotal in making sure the patient gets on the right pathway at the earliest opportunity. GPs look after all aspects of a patient's needs, and in some instances this can mean it takes several appointments to assess any changes that might be indicative of cancer, for example if the patient has multiple morbidities. However, a typical GP will only have around 10 minutes per appointment when making the decision to refer for an investigative test.

Recent findings from the International Cancer Benchmarking Partnership found that UK GPs said they would be less likely to send a patient with potential cancer symptoms for tests, or to refer them to a specialist at their first appointment, than doctors from Australia, Canada, Denmark, Norway or Sweden. The study showed that there is a correlation between these referral patterns and the differences between the countries' one-year cancer survival[74].

In most cases in England, patients presenting with symptoms to a GP are referred after the first or second visit[11]. But in around a quarter of cases, particularly for younger patients, those from ethnic minorities, and those with some types of cancer (where symptoms are less well-known, or they relate to organs which cannot be easily palpated or inspected)[75], patients report visiting their GP three or more times before hospital referral[11]. Furthermore if the initial presentation is with misleading or vague symptoms, and the first test is uninformative, patients can end up shuttling between primary care and different diagnostic services in secondary care, increasing anxiety for the patient and placing greater burden on already over-stretched GP and diagnostic resources. Earlier referral for tests should help to reduce the number of repeat GP visits some patients have to make.

There is no fixed referral threshold in GP practice, but until recently NICE guidelines suggested that patients needed to have symptoms which indicated a five to ten per cent risk of cancer before further tests were carried out. Some commissioners and diagnostic departments in hospitals have stuck rigidly to these guidelines, despite evidence showing that a GP's "gut instinct" could be a helpful additional guide of whether a patient needs to be investigated[76].

The health service needs to ensure that GPs are supported in a system that promotes investigative testing more than it currently does. New NICE guidelines were launched in June 2015, recommending that patients should now be referred for further tests where symptoms indicate a three per cent or higher risk of cancer[77]. Ultimately, there is the opportunity in certain cancers to go further than the thresholds currently set by NICE. Nearly 90% per cent of people would opt for investigation even if their symptoms carried just a one per cent risk of indicating cancer[78]. Even if cancer is excluded, the non-specific nature of most of the tests used may result in earlier diagnosis of another underlying condition, which might also benefit from earlier intervention.

In order for the NICE guidelines to be rolled out, the system will need a significant injection of resource to improve capacity – this is addressed in section 5.2.5. Even with increased capacity, there will be a need to assess how these guidelines are impacting the system, and whether we have the correct mechanisms in place to optimise their effectiveness while maintaining patient safety. This evaluation should include a focus on over-diagnosis and assessing the impact of any increase in false positive test results.
Recommendation 16: We recommend the following to take forward the new NICE guidelines:

- **NICE should work with organisations such as Cancer Research UK, the Royal College of GPs and Macmillan Cancer**

Support to disseminate and communicate the new referral guidelines to GP practices as quickly as possible.

- **By mid-2016, NHS England should evaluate implementation of the new NICE referral guidelines through 2-3 vanguard sites, to assess impact and ensure they are deliverable.**

- **From mid-2016 onwards, subject to there being adequate diagnostic capacity, NHS England should ensure that GPs and other front line primary health services assess the risk of symptoms which could be cancer. They should instigate investigations or referral to diagnostic services in line with the new NICE guidelines. CCGs will also need to ensure that GP clinical judgement is regarded as an acceptable 'flag' e.g. if a GP is concerned about a patient whose symptoms nevertheless do not fit within the new NICE criteria.**

In addition, Health Education England should work with the Royal College of General Practitioners (RCGP) to consider whether GP training needs updating, to include an increased focus on investigative testing for cancer and dealing with and effectively managing uncertainty and risk.

If a patient presents with symptoms, GPs will usually refer them to a secondary care specialist who will then order the investigative test. The specialist will discuss the result with the patient before referring them back to the GP if the test is negative. In many cases, the GP knows which test to order. The potential exists therefore to save both time, and a considerable number of outpatient appointments, if GPs could refer directly for these tests. At present, this is much more difficult than it needs to be in most parts of the country, despite the implications for releasing scarce capacity.
The previous cancer strategy specified that GPs should have direct access to four types of test[x]. As at the end of 2014, only 30% of CCGs commissioned direct access to all four, with 22% commissioning none at all[79]. Only around one in five GPs in England report having direct access to CT and MRI scans, while their counterparts in other countries report having at least twice this level, and in some cases close to 100%[74]. This needs to be addressed, while keeping the option open for GPs to refer to a specialist first should they choose to.

Recommendation 17: NHS England should mandate that GPs have direct access to key investigative tests for suspected cancer – blood tests, chest x-ray, ultrasound, MRI, CT and endoscopy – by the end of 2015.

International studies show that GPs in England have much poorer access to specialist advice than their counterparts in other countries when it comes to optimising decision-making for investigative testing[74]. They need better access to this advice when making difficult referral decisions. CCGs should consider how they can facilitate more regular discussions between primary and secondary care, to optimise referral pathways.

5.2.3 Safety-netting

It is important that GP practices continue to monitor those patients sent for an investigative test. This will ensure test results are reported and communicated, and that any abnormal results are followed up appropriately. This is especially the case if symptoms persist despite a negative test, as further testing or follow up may be required.

Recommendation 18: NHS England should incentivise the establishment of processes by GP practices to ensure 'safety-netting' of patients, including adequate support for training.

5.2.4 Secondary cancer and recurrence

Patients who have previously been diagnosed and treated for cancer are more likely to develop a second cancer or to have a recurrence. It is therefore essential that GPs are particularly alert to symptoms in these patients, and to refer quickly if such symptoms occur.

NHS England should consider incentivising the establishment of processes by GP

[x]Chest x-ray, non-obstetric ultrasound, endoscopy and brain MRI

practices to ensure that patients who have been previously treated for cancer are quickly investigated if they present again with symptoms which could be cancer.

5.2.5 Diagnostic capacity

Diagnostic services are currently under significant pressure. Therefore the ability to undertake a transformational shift in the level of investigative testing is limited. The GP workforce is severely under-resourced; plans are already in hand to increase the numbers of GPs in training[80], although this will take some time to deliver.

There are also capacity deficits in radiology and endoscopy. These deficits act as a "bottleneck" in the system, as well resulting in tests taking longer to report. A recent survey by the Royal College of Radiologists estimated that 330,000 patients across England are waiting more than a month for x-ray results, and almost 8,000 for CT or MRI results[81].

Tackling workforce shortages will take time (see section 8.5.2), and therefore short to medium term measures are needed to support the NHS to deliver tests and results. Not all of the additional capacity needs to be provided in secondary or tertiary settings and there are already good examples across the country of some provision being made available in community settings.

The Government committed £450m to improving early diagnosis in 2011, with one of the main objectives being to improve GP direct access to four key diagnostic tests for cancer[82]. However, it appears that much of this funding was absorbed through other financial pressures and access did not improve sufficiently. Diagnostic services are considered an "overhead" in some hospitals, with providers therefore having little incentive to increase capacity. We therefore recommend taking a different approach to providing increased capacity given the importance of addressing this issue. Most tests will be commissioned through normal processes but there is a need for a national initiative to 'unlock' increases in capacity. A national capacity fund would enable a strategic approach to assisting those parts of the service that have the greatest need to improve. Funding would be distributed based on evidence-based bids and commitments to long-term increases in capacity at a local level. It will be important to ensure that any capacity increases are of high quality.

Recommendation 19: NHS England should establish a national diagnostic capacity implementation fund to unlock the significant increase in diagnostic capacity required to implement higher levels of investigative testing.

So that we can assess the impact of these changes and continue to identify opportunities to improve, it will be essential that we collect all the necessary data in a timely manner and make it accessible. The Diagnostic Imaging Dataset (DID) is a relatively new collection of detailed information about diagnostic imaging tests ordered for NHS patients, although it is not yet possible to identify whether a test was specifically ordered in relation to a suspicion of cancer. DID collects a number of key data points, including waiting times for test requests through to reporting. The National Cancer Intelligence Network (NCIN) is starting to generate results from analysis of this dataset, and it will be important that it is maintained and further improved.

Recommendation 20: NHS England should commission an enhanced Diagnostic Imaging Dataset on a permanent basis.

5.2.6 New approaches to diagnostic pathways

Improvements to existing diagnostic pathways will only take us part of the way to delivering a step change in diagnosing cancer earlier. We know from other countries that there is a range of different models for investigative testing and diagnosis.

The ACE (Accelerate, Coordinate and Evaluate) Programme is an initiative between NHS England, Cancer Research UK and Macmillan Cancer Support. It was established to help improve England's cancer survival rates by providing evidence on how best to design diagnostic pathways. There are 60 projects underway as part of the programme. By mid-2017, Wave 1 of the ACE projects will have been completed and evaluated, generating lessons for commissioners and providers to improve earlier diagnosis.

There are a number of additional areas to be tested alongside the existing concepts being explored through ACE. One current area of weakness is that there is no optimal referral pathway for patients with non-specific but persistent concerning symptoms. These patients often fall through gaps, resulting in delays to diagnosis. Others may end up shuttling between primary and secondary care if the first or second test ordered is uninformative. One model that could address this is the multidisciplinary diagnostic centre (MDC) concept – a single testing location where a patient can undergo several tests relevant to their symptoms on the same day. An MDC could be based in a community or a hospital setting and would supplement diagnostic pathways for 'red flag' symptoms that are more clearly indicative of a particular type of cancer. It would address symptoms for which GPs find it hard to determine the appropriate referral pathway (including 'low risk but no risk' groups) or with which patients tend to present late. These could include persistent vague abdominal pain, fatigue, bloating or weight loss.

Recommendation 21: NHS England should pilot, in up to 5 vanguard sites and in conjunction with Wave 2 of the ACE programme, multi-disciplinary diagnostic centres for vague or unclear symptoms. These should have the capability to carry out several tests on the same day.

We should also explore the feasibility of patients self-referring for investigative tests, particularly in areas where GP access is poor. This would cut out some visits to GPs and help reduce the burden they face. It may also act to reduce the alternative self-referral pathway i.e. to the emergency department. Self-referral would only be appropriate for patients who clearly have "red-flag" symptoms and would therefore ordinarily automatically be referred for a test, i.e. persistent rectal bleeding, difficulty swallowing, breast lump or blood in urine. In order to do this without over-burdening the system with the 'worried well', we need to evaluate whether a triage system (for example a nurse-led telephone conversation) would need to be put in place.

Recommendation 22: NHS England should pilot an approach, through new or existing vanguards, and particularly in areas where GP access is known to be poor, through which patients can self-refer for a first investigative test via a nurse telephone triage, if they have a red-flag symptom that would always result in a test.

A further alternative approach would be to pilot the role of a cancer nurse specialist in large GP practices, who could act as a coordinating presence for cancer diagnostic pathways and screening. These nurses could also coordinate recurrent symptom triage, treatment-related symptoms, and follow up.

Recommendation 23: NHS England should pilot the role of a cancer nurse specialist in large GP practices to coordinate diagnostic pathways and other aspects of cancer care.

Figure 16 illustrates the range of referral pathways that will be taken forward.

To a large extent, approaches to improve early diagnosis focus on cancer in its broadest sense. These initiatives could support expedited diagnosis across a large number of cancer types. However, there are some cancers where some specific factors

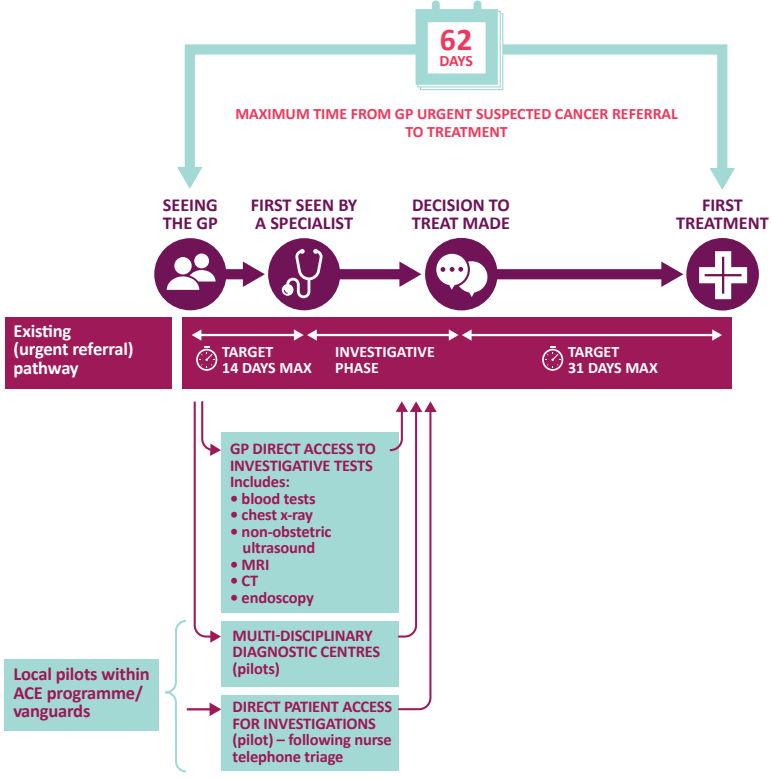


Figure 16: New referral pathways

in children, where a disproportionate number present through emergency routes[51]. We need to understand better why this is the case, so that we can tailor initiatives accordingly. It may be there are some specific symptom patterns that parents of young children should be alert to. In this case, these could be communicated in a similar way as symptoms of meningitis, since the incidence rates are similar[xi]. Public Health England and NHS England should evaluate data from the HeadSmart programme to determine what factors influence late diagnosis of brain tumours in children and whether tailored initiatives would be appropriate.

Finally, NHS England should work with NIHR and research charities to determine how best to monitor and evaluate emerging point-of-care triage tests and decision support tools which could be used in primary care to stratify referrals for further investigation. Often these tests are developed by small companies which do not have the resource or expertise to undertake large scale trials to validate their use.

5.2.7 Measuring performance on early diagnosis

Regular monitoring of how well we are doing in reaching a definitive cancer diagnosis or excluding cancer quickly is crucial. The success of initiatives in transforming the diagnostic pathway are reliant on this. The current system is measured by how it performs under a two-tier approach. This includes the urgent referral pathway for the first test for patients with red flag symptoms. We propose that this is no longer needed, and indeed that it could be causing unnecessary complexity and "system gaming". All referrals for testing for possible cancer should be considered as urgent, and the system should be able to deliver this if extra diagnostic capacity is put in place.

There are a number of elements of the pathway measured currently. However, none capture the whole time elapsed from GP referral for a test to the patient receiving details of a definitive diagnosis or cancer exclusion. We should aim for this entire process to be achieved for all patients within 4 weeks. Focusing on the entire time taken will encourage commissioners and providers to consider how best to streamline and optimise diagnostic pathways for the vast majority of patients (see Figure 17). The only exceptions to the four-week ambition should be where a patient chooses to delay, given that a definitive diagnosis of cancer will usually only be possible after a biopsy, i.e. following the first or second investigative test. For example, some patients with possible prostate or brain cancers may choose to take time considering whether they wish to have a biopsy, given the potential risks.

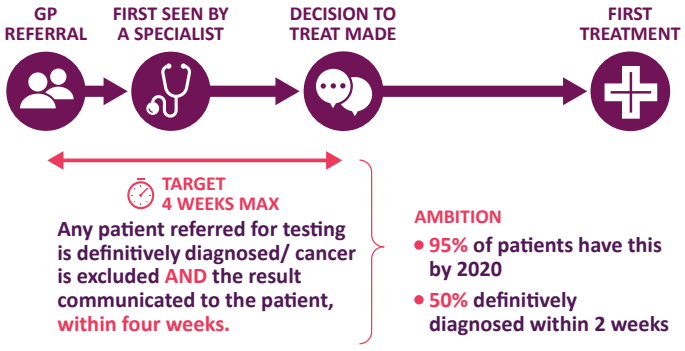


Figure 17: New diagnosis metric

Recommendation 24: By the end of 2015, NHS England should develop the rules for a new metric for earlier diagnosis measurable at CCG level. Patients referred for testing by a GP, because of symptoms or clinical judgement, should either be definitively diagnosed with cancer or cancer excluded and this result should be communicated to the patient within four weeks. The ambition should be that CCGs achieve this target for 95% of patients by 2020, with 50% definitively diagnosed or cancer excluded within 2 weeks. Once this new metric is embedded, CCGs and providers should be permitted to phase out the urgent referral (2-week) pathway.

Even with implementation of the recommendations set out in this chapter, some patients will continue to be diagnosed through an emergency presentation. Such diagnoses represent a learning opportunity for all concerned, as Significant Events. We should ensure that this opportunity is

[xi] There is evidence from other countries that more regular health checks during school can lead to more cancers being found early[83]. For example, the volume of a childhood renal tumour at diagnosis in England is on average double that in France or Germany, since in these countries many more tumours are detected before symptoms appear.

grasped, not least as the burden on each GP will be manageable, at around 1-2 such diagnoses per year on average.

Recommendation 25: All GPs should be required to undertake a Significant Event Analysis for any patient diagnosed with cancer as a result of an emergency admission.

5.2.8 Teachable moments

The majority of individuals who have an investigative test following presentation with symptoms, will have had contact with the healthcare system, and many will have experienced considerable anxiety. As such, they will be focused on their health, and many will be more receptive to messaging around lifestyle risk factors and symptom awareness. This represents a 'teachable moment' which could be used to help people modify aspects of their lifestyles to reduce of a variety of conditions. The health service needs to capitalise on these opportunities. Advice could be given by the GP, the diagnostic clinician, or another health care professional. Innovative approaches to the use of non-clinical roles could free up more opportunities for such 'moments.'

The NHS, local authorities and social care have already had success with the 'Making Every Contact Count' initiative. This encourages conversations based on behaviour change methodologies (ranging from brief advice, to more advanced techniques). This experience should be built upon.

5.3 TREATMENT

Continued growth and ageing of the population will drive increases in demand for NHS cancer services. Improvements in early diagnosis will mean more patients will require access to treatments that offer them the best outcome. As stated in the FYFV, 'it is not enough to improve the rates of diagnosis unless we also tackle the current variation in treatment and outcomes'. Most cancer patients will need a combination of surgery, radiotherapy and chemotherapy. It is essential that planning for improvements in, and provision of, these treatments does not consider them in isolation. Modern practice requires an integrated approach to treatment and care.

5.3.1 Surgery

Surgery is the cornerstone of treatment for a number of cancers. It is estimated that surgical intervention contributes to around half of cases where cancer is cured[84]. Advances in surgical techniques have seen increased use of less invasive procedures, which can reduce recovery times and improve patient experience. Developments such as enhanced recovery programmes have enabled patients to receive the best possible care before and during their operation, reduce length of stay and improve patient experience. These programmes are increasingly being made available in all hospitals.

Over the last 15 years, there have been significant reductions in variation in practice. This has come about through centralisation, specialisation, peer reviews and multidisciplinary teams becoming widely embedded in practice. However, variations in surgical activity and outcomes from surgery remain across the country. For example, the proportion of patients diagnosed with lung cancer who are treated surgically has been found to be as low as 6% in some hospitals and as high as 31% in others[85]. Overall, the proportion of patients undergoing potentially curative surgery for lung cancer in the UK is 15%[85], compared with 17% in other countries in Europe and 21% in North America[86].

5.3.1.1 Service configuration for surgery

There is growing evidence that specialist surgeons practising in high volume hospitals produce better outcomes for patients for certain procedures[87]. For example in Denmark the number of hospitals that perform colorectal cancer surgery has been reduced by two thirds and this has resulted in a 62% improvement in post-operative mortality after two years[26]. The complication rate is the same in smaller centres, but expert opinion suggests that bigger centres have greater experience in "rescuing the patient" if something goes wrong. Significant evidence exists to support centralisation of surgery for particular tumour groups, for example upper GI, brain, rectal, urological,

lung and gynaecological cancers. However, there are gaps in the evidence base for many other tumour groups or procedures.

Surgery tends to involve a small number of hospital visits, whereas most radiotherapy and chemotherapy is delivered in multiple doses over many weeks. So it may be less burdensome for patients to travel for their surgery to centres where volumes are higher and outcomes better. Nevertheless, the option of increasing centralisation further needs evaluation. We need to balance the opportunities for improved outcomes through greater specialisation, with the implications for patients having to travel further. We must also take into account the need for general surgical cover in smaller hospitals, and ensuring the availability of a broader team infrastructure to support patients.

Recommendation 26: CRGs should regularly evaluate emerging evidence to determine whether service configuration for surgery merits further centralisation and advise NHS England accordingly. Any reconfiguration should be undertaken with regard to broader commissioning and patient experience factors (see section 8.1).

Recommendation 27: NCIN should undertake an up-to-date evaluation of the impact on cancer outcomes of patients living different distances from a cancer Centre. Historical data suggested that longer distance from a Centre results in lower probability of curative treatment. We need to understand if this is still the case.

5.3.1.2 Measuring surgical performance and reducing variation

Surprisingly, there is no published consensus on how best to measure quality in surgery across most cancer types (although we do have exemplars such as the Bowel Cancer Audit). Transformation of services where needed would be facilitated if we could measure performance consistently, against an agreed set of metrics. This would also support reductions in variation in practice across the country. There is widespread appetite for more transparent information on clinical outcomes. However publication of surgeon-level data is not necessarily meaningful in cancer. Good outcomes for patients do not just rely on what happens in theatre. They are also dependent on the people involved in preoperative assessment and postoperative care, and the organisation of processes and infrastructure in place.

Recommendation 28: The Royal College of Surgeons of England and Royal College of Surgeons Edinburgh, working with Clinical Reference Groups, NCIN, Care Quality Commission (CQC) and Cancer Research UK, should lead a process to define, by mid 2016, key quality metrics for each cancer surgery sub-speciality. Any new data collection should start in 2016 and then be incorporated in service specifications.

5.3.1.3 Timely surgery

Hospitals in England have been under significant pressure over the last few years. This has resulted in missed targets and elective surgery being cancelled in some cases, for example due to lack of ITU and ward bed space. We don't yet have a full understanding of the impact this has had in cancer. But anecdotal evidence suggests it has led to trusts cancelling procedures for some cancer patients in some parts of the country. While service pressures remain, NHS England should actively monitor the number of cancer patients who have their elective surgery cancelled.

5.3.2 Radiotherapy

Radiotherapy can cure cancers, can assist in alleviating symptoms and is cost effective. It is second only to surgery in its effectiveness in treating cancer, and experts suggest around 4 in 10 patients whose cancer is cured receive radiotherapy[84]. Thirty eight per cent of cancer patients in England currently have radiotherapy as part of their treatment[88]. International benchmarks suggest this should be closer to 50 per cent[89].

Recent advances in radiotherapy using cutting-edge imaging and computing technology have helped target radiation doses more precisely. As a result, they enable better outcomes, with improved quality of life for patients and reduced NHS

costs in the long term, through patients suffering fewer side effects. Historically the NHS has not adopted new techniques into clinical practice in a consistent and equitable way across England. In 2014, NHS England and Cancer Research UK jointly published a Vision for Radiotherapy. This recommended that all patients should receive advanced and innovative radiotherapy that had been shown to be clinically and cost effective.

Initiatives to drive adoption have had some success. The Radiotherapy Innovation Fund implemented within the last Parliament was instrumental in raising the proportion delivered by Intensity Modulated Radiotherapy (IMRT) from an average of 8% to the interim target of 24% within 18 months[90]. However there is further to go. The proportion of IMRT varies from 22% to over 70% across England, with 2 centres still not consistently hitting the 24% minimum[91].

Stereotactic radiosurgery (SRS) and stereotactic radiotherapy (SRT) are treatment options that are also becoming routine in clinical practice, for example for the treatment of cerebral metastases and skull-based tumours. Provision of these treatment options needs to be more consistently commissioned. Demand for SRS/SRT services is estimated to grow by 35% per annum over the next several years[92].

5.3.2.1 Radiotherapy machines

As radiotherapy becomes more sophisticated, there is a need for greater support and investment in equipment, software and training. New technology platforms may require greater investment than a standard linear accelerator (LINAC). However, this is offset by modern LINACs being markedly quicker and offering higher throughput. New treatment protocols also demonstrate that fewer doses (or "fractions") can often be used, while achieving the same efficacy. Therefore, we may not need to see an increase in the number of LINACs despite the rising number of people being diagnosed with cancer, provided that LINACs are up to date technically and being used optimally.

It is recommended that LINACs are replaced after 10 years in operation to assure patient safety and enable up-to-date innovations[93].

The latest audit of radiotherapy equipment shows that 126 LINACs were between 5 and 9 years old in 2013, meaning they should be replaced in the next three years. A further 58 LINACs will need upgrading in the next three years so we can deliver more innovative treatments. However, financial pressures in hospitals are precluding LINACs being replaced or updated in a timely way. It is not in the interests of patients or cost-effective that we allow this situation to persist.

NHS England should take a coordinated approach to radiotherapy equipment in England, possibly through a centralised procurement process. A rolling programme of replacements will enable more rapid implementation of new radiotherapy techniques and more effective use of the radiation oncology workforce. This programme will need to ensure that treatment planning systems and software licenses are updated alongside capital investment.

Recommendation 29: From autumn 2015, NHS England should commence a rolling programme of replacements for LINACs as they reach 10-year life, as well as technology upgrades to all LINACs in their 5th year. All LINACs that are already ten years old should be replaced by the end of 2016 at the latest. This should be driven through a national capital fund, overseen in the first 2-3 years by a small implementation team, who will also need to ensure that equipment is geographically distributed to serve local populations optimally.

5.3.2.2 Radiotherapy imaging

The use of imaging in treatment planning and delivery improves and verifies the accuracy of radiotherapy. The greatest improvements in radiotherapy over the next ten years will likely be driven by advances in imaging technologies. Access to Magnetic Resonance Imaging (MR) and Positron Emission Tomography (PET) for use in radiotherapy planning is varied across the country. This is impacting on the ability to meet waiting time targets for treatment to start. There are recommendations in this strategy to increase imaging capacity more broadly. However, it will increasingly be inefficient to use these facilities both for diagnostic purposes and for radiotherapy

planning. It is estimated that for every 2-4 million population served by a Centre, 0.7 of an MR machine is required, i.e. approximately 15-20 MR machines across England, at a total capital cost of less than £10m[xii].

Recommendation 30: As part of the national radiotherapy capital fund, NHS England should support the provision of dedicated MR and PET imaging facilities for radiotherapy planning in major treatment centres.

5.3.2.3 Radiotherapy and interventional radiology research

The portfolio of radiotherapy research in England is now growing following a sustained period of under-investment. It is expected to continue to grow over the next decade, leading the world in the development of the evidence base for new innovations. This will require further investment from research funders, with concomitant support from the NHS. In particular, the following techniques need further research:

- Stereotactic ablative body radiotherapy (SABR)
- Proton beam therapy (PBT)
- Adaptive radiotherapy based on advanced imaging (including the MR-Linac)
- Combinations of radiotherapy with novel drugs
- Biomarker selection for altered radiotherapy strategies
- Molecular Radiotherapy (MRT) and brachytherapy trials.

It will also be necessary to evaluate the use of new interventional radiology techniques, compared with conventional radiotherapy and some surgical techniques. Alongside new innovations, continued studies of hypo-fractionation opportunities could result in reduced treatment costs as they have historically.

Estimates suggest that patient numbers across all these areas will rise to about 1500 per annum in clinical trials over the next ten years. Ensuring that these trials take place should be a priority for the NHS.

Radiotherapy demands significant financial investment; it is critical that we have the evidence base on which to support this investment (see section 5.9.1).

5.3.3 Chemotherapy and systemic treatment

Chemotherapy and other systemic therapies play a vital role in the treatment of cancer. They are estimated to contribute to around 1 in 10 cancer cures in their own right. They also play a crucial role in combination with other treatment modalities, for example by helping to shrink tumours so they can be targeted with surgery or radiotherapy.

A recent report has looked at drug usage across European countries. The findings show that the UK has increased its use of medicines launched in the last five years, rising from 10 to 7 in the ranking since 2008/09[94]. We have a disproportionately higher use of medicines that were launched more than 10 years ago, with our ranking going from 9 to 4. Our use of cancer hormones and drugs launched 6 – 10 years ago is reducing.

5.3.3.1 Access to innovative drugs

The Cancer Drugs Fund has helped more than 72,000 cancer patients in England access the drugs their doctors think they need in the absence of NICE approval[95]. It has enabled pull through of innovative drugs into routine NHS use. However, because it has also enabled some pharmaceutical companies to bypass NICE cost-effectiveness assessments, it is widely acknowledged that it is no longer sustainable or desirable for the Cancer Drugs Fund to continue in its current form. In its place a solution is needed that ensures patients have routine access to a greater range of cancer drugs, including earlier access to innovative drugs, while ensuring that cost-effectiveness is maintained. A process is under way to find such a solution and it is anticipated that this will be agreed by summer 2015. Part of the solution will continue to be a national fund to make new cancer treatments available prior to NICE assessment or which are subject to a conditional approval.

[xii] Research commissioned for the Taskforce, as yet unpublished

Recommendation 31: NHS England should work with NICE, the Government, the pharmaceutical industry and cancer charities to define a sustainable solution for access to new cancer drugs. This updated process should enable NHS England to confirm clinical utility, whilst managing within a defined budget, and should be aligned with NICE appraisal processes. The new process should be published for consultation in summer 2015, with a view to implementation from April 2016. The solution should set out reforms to NICE processes to make them more flexible for cancer drugs.

In recent years, a number of immunotherapy drugs have been developed, and are showing significant promise. They could be 'game changers' due both to the magnitude and durability of their effect in some patients and the number of different tumour types implicated. We will have to handle adoption of these therapies within the NHS carefully, as they have a different profile of toxicities and side effects to many of the treatments currently in use. There could also be major implications for the training and size of the medical oncology workforce and how some cancer services are delivered.

Recommendation 32: The chemotherapy Clinical Reference Group (CRG) in NHS England should establish an expert working group to monitor emerging evidence and advise on the use of immunotherapies in different types of cancer, considering the implications for funding, roll-out and workforce.

5.3.3.2 Delivering chemotherapy closer to patients

Across England there is a range of models in place to deliver chemotherapy, dependent on resource availability and the population being supported. One model being developed in several forms is that of delivery in community settings, for example nurses from a secondary care provider delivering chemotherapy in GP premises. The majority of patients prefer receiving chemotherapy closer to home where possible. Cost-efficiencies within the system can be also achieved through better management of chemotherapy units. However, it is imperative to clarify which drugs are safe enough to be delivered in community settings, and at what doses, for these models to be rolled out more broadly. Patient safety and management of side-effects need to be paramount. It is unlikely to be cost-effective over the next five years to deliver much chemotherapy at home given the increasing complexity of treatment regimens and their associated side effects.

Recommendation 33: NHS England should encourage the delivery of chemotherapy in community settings by sharing examples of good practice nationally. The chemotherapy Clinical Reference Group should publish a list of drugs which are safe to give in community settings.

5.3.3.3 Electronic prescribing

Electronic prescribing of all cancer medicines has been mandatory for providers since 2006, because of the clear and well-evidenced implications for patient safety of manual prescribing. However, the latest national Peer Review report identified that 59% of clinical teams still do not comply fully.

Recommendation 34: Monitor and NHS England should introduce new sanctions for any provider not fully complying with electronic prescribing by March 2016.

5.3.3.4 Data on drug usage

Until recently there has been no national collection of data on cancer drug treatment. The Systemic Anti-Cancer Therapy Dataset (SACT) was established in 2012 to address this. For the SACT to achieve its potential, it is essential that all providers submit data regularly and consistently. Doing so will support service development and commissioning. It will enable a better understanding of drug usage, such as compliance with NICE guidelines, and an understanding of the proportion of drug spend consumed in the last weeks of life.

Recommendation 35: CQC should ensure that assessment processes for providers incorporate submission of data in a timely manner to SACT.

5.4 MOLECULAR DIAGNOSTICS

We understand increasingly that cancers

which arise in the same part of the body and appear the same by conventional pathology may have highly heterogeneous prognoses, determined by specific molecular changes in the individual patient's cells. This results in varying risk of developing cancer and response to treatment. Our evolving understanding is critical for optimising prevention and effective treatment in the future. However, other than in a few leading centres, we don't yet have means to distinguish such patients in a systematic, quality-assured way. Increasingly, we are falling behind some other countries in the use of molecular diagnostics to deliver the best and most cost-effective care.

5.4.1 Stratified approaches to prevention and screening

All cancers develop because something has gone wrong with one or more of the genes in our cells. It is relatively rare for people to develop cancer because they have inherited a genetic fault that increases their risk. For example, only around 2 per cent of breast cancers are associated with BRCA1 or BRCA 2 mutations[96,97]. However, our knowledge of these genetic faults is now advanced enough to offer the potential to implement active surveillance for individuals at high risk.

Hereditary non-polyposis colorectal cancer (HNPCC), also known as Lynch Syndrome, is an inherited genetic mutation that increases bowel cancer risk. Genetic tests are available that can detect HNPCC mutations in affected people. Lynch Syndrome accounts for around 5% of colon cancers[45]. Around 9 in 10 males and 7 in 10 females with HNPCC develop bowel cancer by age 70. Lynch Syndrome also increases the risk of developing other cancers, including womb and ovarian cancer in women, and less frequently stomach, small bowel and gallbladder cancers. Testing of people diagnosed with bowel cancer under the age of 50 is vital to help identify people with Lynch Syndrome and it has been shown to be cost-effective. It is currently mandated by the Royal College of Pathologists, but many hospitals do not perform this test[98].

Faulty BRCA genes are rare. However, between 45 and 90 per cent of women with a mutated BRCA1 or BRCA2 gene will develop breast cancer during their lifetime[99]. NICE has developed a guideline on familial breast cancer to address the needs of this group. These genes also increase the risk of ovarian cancer and BRCA2 increases the risk of male breast cancer and prostate cancer. Between 40 and 60 per cent of women with a faulty BRCA1 gene, and between 10 and 30 per cent with a faulty BRCA2 gene, will develop ovarian cancer at some point in their lives. Testing women at the point of diagnosis can ensure access to the most relevant treatment and enable family members to understand their own risk and take preventative action where appropriate. This may include more regular screening, use of chemo-preventive agents such as tamoxifen, or other measures.

Recommendation 36: NHS commissioners should ensure that:

- **All patients under the age of 50 receiving a bowel cancer diagnosis are offered a genetic test for Lynch Syndrome.**
- **All women with non-mucinous epithelial ovarian cancer are offered testing for BRCA1/BRCA2 at the point of diagnosis.**
- **All women under the age of 50 diagnosed with breast cancer are offered testing for BRCA1/BRCA2 at the point of diagnosis.**

These tests will enable any family members at high risk to be identified and active surveillance programmes put in place. Where applicable, positive tests should guide decisions on the most clinically and cost-effective prevention interventions or treatments.

5.4.2 Stratified cancer drug treatment

We now have a number of licensed medicines which have been designed to target specific genetic mutations or other abnormalities in a patient's cancer. These targeted medicines can improve outcomes for certain patient groups, providing greater progression-free or overall survival and avoidance of undesirable side-effects for those patients for whom these treatments will not work. Patients can experience many months or years of extra survival plus a much

better quality of life depending on the type of cancer and specific medicine (see Figure 18).

Molecular diagnostic tests are well established in the NHS for haematological cancers and for HER-2 and ER testing in breast cancer. For other solid cancers, most molecular diagnostic tests available in the NHS currently test for one genetic mutation linked to one potential drug. However, a multiplex panel approach is rapidly becoming a realistic option. This would mean that one panel could run a number of analyses simultaneously. This is becoming increasingly important, since some drugs indicated through one genetic mutation may be contra-indicated if there is the presence of another mutation in a different gene. Secondly, multiplex testing enables clinicians to identify if there is a specific mutation present which would suggest the patient may be suitable for a treatment indicated for another condition. Ultimately, it may be appropriate to move to whole genome sequencing, but this is not yet appropriate for most types of cancer other than in a research setting.

Molecular testing activity to guide treatment for solid tumours in England has increased by an average of 51% per year since 2011. The majority of these tests are on non-small lung cancer patient tumour samples[xiv]. However, an estimated 24,000 molecular diagnostic tests were not undertaken in 2014 based on the projected demand of 89,000 tests in England[xv]. This meant that

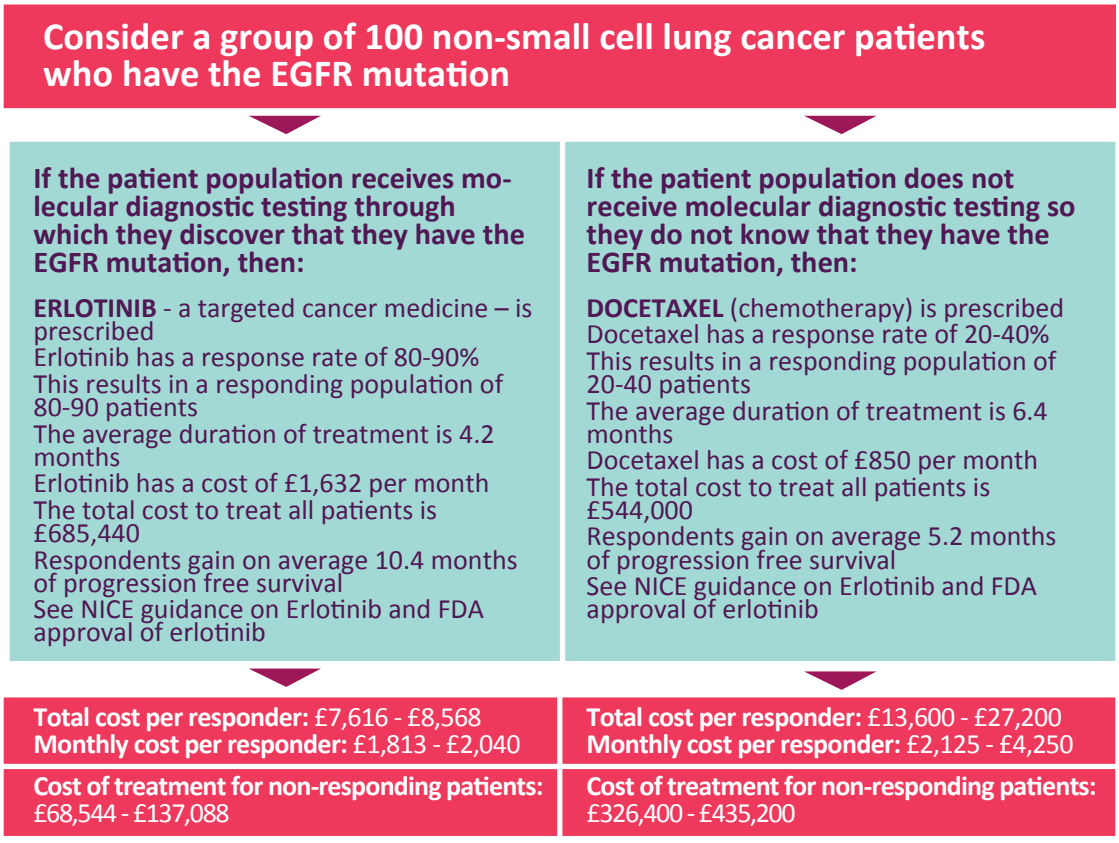


Figure 18: Case study of lung cancer patients with EGFR mutation[xiii]

an estimated 3,500 patients with colorectal or non-small cell lung cancers may have missed the option of a targeted medicine. The primary reason for the shortfall in testing is that there is no national tariff or approach to commissioning. Furthermore, the increase in molecular diagnostic testing we have seen since 2011 has been driven through pump-priming by the relevant pharmaceutical company. This is usually withdrawn after a period of time and the NHS cannot rely on this approach going forward if we are to optimise outcomes for patients[xvi].

As well as targeted medicines, stratified approaches can also indicate where existing

[xiii] Research commissioned to inform Taskforce, as yet unpublished
[xiv] Research commissioned to inform Taskforce, as yet unpublished
[xv] While testing is undertaken for a variety of reasons, these figures focus on testing for solid tumours for which an approved targeted medicine is routinely available on the NHS.

chemotherapy treatments should be avoided, since patients do not benefit from them, but experience side-effects which have to be managed. For example, the use of the chemotherapy drug 5FU as a treatment for colorectal cancer has much lower efficacy for patients with mutations in mismatch repair genes (approximately 12-15% of all such patients). In certain types of breast cancer[xvii], the benefit of adjuvant chemotherapy is very uncertain. NICE has recommended a particular test to enable patients to avoid such chemotherapy and its side effects. This would enable a considerable saving for the NHS in treatment costs also. However, this test is not yet routinely commissioned.

Recommendation 37: NHS England should transform access to molecular diagnostics to guide treatment for cancer:

- **NHS England should nationally commission access to molecular diagnostic tests to guide treatment, starting with the following cancer types in 2016: melanoma, lung, colorectal, breast and all paediatric cancers. This would be in addition to haematological cancers, with a further broadening out to all cancer types where treatments are already subject to a molecular diagnostic test by 2020.**

- **Use of molecular diagnostic tests by providers should be added to the COSD data set.**

- **NHS England should undertake a year by year review of molecular diagnostics capacity given the pace of scientific and technological advance.**

- **NHS England should develop plans to move to a validated multiplex molecular diagnostic panel by end 2016[xviii].**

The NHS 100,000 Genomes project aims to use genomic medicine to transform the way people are cared for and to position the UK as a world leader in genomics technology and its application. The project will sequence 50,000 genomes from around 25,000 cancer patients, combining sequence data with medical records, leading to a ground-breaking resource for researchers. It is hoped that the outcomes of this project will help inform the future of cancer medicine, enabling us to predict, prevent, personalise and precisely diagnose.

5.5 ENHANCING TREATMENT SERVICE DELIVERY

5.5.1 Multi Disciplinary Teams

The model of Multi Disciplinary Team (MDT) working has revolutionised our approach to cancer treatment over the past 15 years. MDTs have also delivered a number of improvements in the quality of care and patient outcomes. They are seen as the 'gold standard' in terms of cancer patient management and have made a substantial contribution to reducing variation in access to treatment.

However, like all parts of the service, they are under growing pressure from increased demand and insufficient support, and are not operating as effectively as they could. They need to be supported to streamline their processes and identify opportunities to reform where possible. They should be supported to use validated tools to self-assess and improve their effectiveness. This will enable us to make the best use of scarce specialist time. MDT discussions should focus more on difficult cases and processes should be put in place to enable swifter decisions on patients going through standard treatment pathways. More emphasis should be placed on learning from patients who have gone through treatment, to improve decision-making. For example, a number of patients die within weeks of active treatment. There may be opportunities to reduce the intensity of treatment in the last weeks of life, to enable improved quality of life and possibly even to enhance patient safety.
Recommendation 38: NHS England should encourage providers to streamline MDT processes such that specialist time is focused on those cancer cases that don't follow well-established clinical pathways, with other patients being discussed more briefly.

[xvi] AstraZeneca has withdrawn funding for molecular tests for NSCLC from 2014 and Pfizer has indicated that it will do likewise
[xvii] ER positive, HER-2 negative, node negative
[xviii] A number of panels are in development, including that developed by Illumina for use in Cancer Research UK's stratified medicine programme across the UK.

Recommendation 39: NHS England should require MDTs to review a monthly audit report of patients who have died within 30 days of active treatment, to determine whether lessons can be learned about patient safety or avoiding superfluous treatment.

One of the most innovative models of MDTs has been in areas where the number of cases is very small, but the treatment options carry high risks, such as in some paediatric cancers. Monthly national video conferences enable local specialists to access national expertise. This is supplemented with an annual audit where every death is discussed, and performance metrics for each unit are compared with the national average. This model has shown to be effective in ensuring that all patients receive a national standard of care, and that continuous learning takes place. There are other types of cancer that could benefit from this approach.

Recommendation 40: The Trust Development Authority, Monitor and NHS England should strongly encourage the establishment of national or regional MDTs for rarer cancers where treatment options are low volume and/or high risk. Clinical Reference Groups will need to play a key role in supporting these.

5.5.2 Acute oncology services

In response to an NCEPOD report which showed serious deficiencies in the care of acutely unwell cancer patients, acute oncology services have been rolled out across England since 2009. They exist in all hospitals that have emergency departments or are specialist cancer hospitals. Their role is to address both the needs of patients presenting as emergencies prior to diagnosis, as well as dealing with acute consequences of treatments provided to patients. However, there has been no coordination of this roll-out. Therefore implementation has inevitably been variable. To date, there has been no systematic evaluation of the impact of these services other than assessment by national peer review. NHS England should commission an evaluation of acute oncology services to understand their impact on outcomes and patient experience. The evaluation should consider efficiency and determine key success factors and other lessons which can be shared nationally. In addition, the roll-out of clinical standards for seven day services across England will, in some respects, go further than the standards set out for acute oncology services, and so it will be important to reassess them.

5.6 SPOTLIGHT ON TARGET GROUPS

5.6.1 Older people

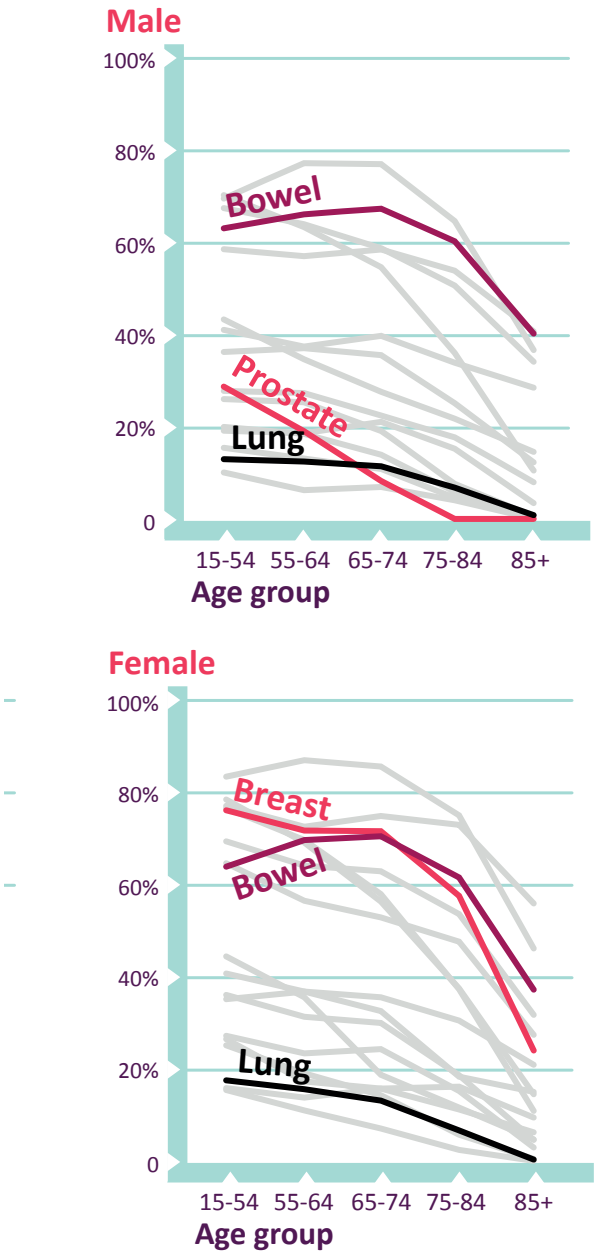
More than a third of cancer diagnoses occur in people over the age of 75[3]. Like all cancer patients, the needs of all older people vary. Type of cancer, socio-economic status, gender and ethnicity all play a role in shaping people's needs and outcomes. Active older people in otherwise good health are very different from those who are frail or who may have other health conditions.

In all countries, cancer survival for older people (75 and above) tails off markedly compared with survival for younger age groups (e.g. 55-64). In England, there is a 20% absolute differential in one-year survival between these age groups. This differential has not narrowed at any time in the last 20 years. Older people are more likely to have their cancer diagnosed late[100]. The proportion of cancers diagnosed in England after an emergency presentation increases with age (although children, teenagers and young adults also disproportionately present as emergencies). Thirty three per cent of all cancers in those aged 80 - 84 in 2006-2010[xix] were diagnosed after an emergency presentation, compared with 15% of cancers in those aged 50-59[51].

In addition, there is a growing body of evidence to suggest that older patients are less likely to receive the most clinically effective and appropriate treatment for their cancer[100 101] (see Figure 19). There are many possible reasons for this. They may face multiple morbidities meaning they are less able to tolerate treatment; they may choose to forego treatment; or they may not be offered optimal treatment because of their

[xix] 24% in those aged 70 – 79 years

age. Some patients may be carers for other individuals and so may be unable to agree to a treatment regimen that requires multiple visits to hospital over many weeks.



gure 19: Percentage of resections by cancer site and age-group (2006-2010, England)[65]

Assessing an older person with cancer and deciding on the most appropriate treatment can be complex. Current assessment methods are not fit for purpose, often resulting in older people's needs not being identified or sufficiently well understood[102]. Specialist geriatricians have increasingly become integrated in to care pathways in orthopaedics. The result has been improved patient outcomes and a revolution in the approach to hip fracture. There may be similar opportunities in cancer care. There is a need to test a more integrated care pathway for older cancer patients, including defining a role for geriatricians to liaise with MDTs on Allied Health Professional (AHP) needs and co-morbidities.

Recommendation 41: NHS England, the Trust Development Authority and Monitor should pilot a comprehensive care pathway for older patients (aged 75 and over in the first instance). This pathway should incorporate an initial electronic health needs assessment, followed by a frailty assessment, and then a more comprehensive geriatric needs assessment if appropriate. The pilot should evaluate a model in which the outputs of these assessments are considered by the MDT in the presence of a geriatrician, who would advise on AHP needs, co-morbidities etc, and their implications for treatment and emotional and physical support.

Recommendation 42: NHS England should ask NIHR and research charities to develop research protocols which enable a better understanding of how outcomes for older people could be improved.

5.6.2 Children, teenagers and young adults

Cancer services for children, teenagers and young adults (CTYA) have improved significantly and deliver better outcomes for patients. In children (aged 0 – 14) in particular, five-year survival has increased from 40% in the early 1970s to 82% today[103]. However, some types of children's cancer remain very hard to treat. Furthermore, many patients suffer long-term physical and psychological consequences of their treatment in to adulthood. Over the last few decades, the impact of some of these longer-term consequences has reduced, as we have better understood them and reduced the intensity of treatments given. The NHS needs to consider the best structure for CTYA cancer services to ensure we continue to improve on the care and experience that patients receive. Outside London, only four centres[xx] treat more than 100 children with cancer per year, across all types of cancer. There is an opportunity to consider whether outcomes could be

improved through further reconfiguration of services. Any review should be based on patient outcomes, including patient experience, as few centres offer comprehensive specialist services for children. Transitions continue to pose a problem in some areas, with paediatric services stopping at 16 in some hospitals but adult services not starting until 18. In addition, pathways between specialist centres and shared care units currently cause a great deal of difficulty for patients. This needs to be addressed.

Recommendation 43: NHS England, working through the CTYA Clinical Reference Group should:

- **Consider whether paediatric treatment centres should be reconfigured to provide a better integrated network of care for patients and families.**
- **Establish clear criteria for designation and de-designation of treatment centres for TYA patients.**
- **Ensure that any transition gap between children's' and adult services is addressed.**
- **Assess impact of proposals on travel times for families.**

The numbers of children, teenagers and young adults with cancer is relatively small. Therefore they represent a cohort of cancer patients in which we could try new approaches to continuous learning, outside traditional clinical trial settings. The use of patient data to understand how patients are progressing through services, together with analysis of tumour tissue to understand the molecular features of their cancer, could transform our approaches in the years ahead. There are a number of important questions such initiatives would enable us to address, which could ultimately improve services for all patients.

Recommendation 44: NHS England should set an expectation that all children, teenagers and young adults diagnosed with cancer should be asked at diagnosis whether they consent for their data and a tissue sample to be collected for use in future research studies and development of services. NHS England should work with research funders to make best use of these resources in the future.

Paediatric cancer survival rates may have been improving (in most cancers), but success has been less remarkable in teenagers and young adults. This may be because a far smaller proportion of TYA patients (15+) take part in clinical trials than younger children. Patients and their families would like increased opportunities to be involved in trials, with access to innovative treatments that wouldn't otherwise be available to them. England has the potential to lead the world in providing opportunities for teenagers and young adults to take part in these trials.

Recommendation 45: NHS England should ask NIHR and cancer research charities to consider ways in which access to clinical trials for teenagers and young adults with cancer could be significantly increased. NHS England should set an expectation that all Centres or designated units treating TYA patients should aim to recruit at least 50% of those patients to clinical trials by 2025.

5.6.3 Patients with metastatic cancer

People with metastatic cancer have unique needs. It is estimated that there are more than 150,000 people living with advanced and incurable bowel, breast and prostate cancer across the UK[104]. These patients' cancers may ultimately be terminal. But they may live for many years and metastases may appear some years after the initial tumour. We should strive for the same significant improvements in survival for patients with secondary cancers as seen for many primary cancers. We also need to ensure this patient group is recognised as distinct by MDTs when planning care.
Recommendation 46: The Trust Development Authority, Monitor and NHS England should encourage MDTs to consider appropriate pathways of care for metastatic cancer patients. Clinical Reference Groups will need to play a key role in supporting these MDTs.

[xx]Birmingham, Manchester, Cambridge and Bristol

Bisphosphonates were originally licensed to treat bone fractures in adults with advanced breast cancer. However, a large meta-analysis of more than 20 randomised control trials has shown that these drugs can help post-menopausal women treated for early breast cancer. The research shows they reduced the risk of breast cancer spreading to the bone by 28% and the risk of dying from breast cancer by 18% after ten years[xxi].

A further meta-analysis of more than 9 randomised control trials has shown that in the same patient group, aromatase inhibitors reduced the risk of dying from breast cancer by 15% compared with tamoxifen, or by around 40% compared with no endocrine treatment, after ten years[xxii]. Furthermore, the use of bisphosphonates and aromatase inhibitors can be complementary.

Recommendation 47: NHS England should commission NICE to develop updated guidelines for adjuvant treatment for breast cancer. Updated guidelines should consider the use of bisphosphonates and aromatase inhibitors to prevent secondary cancers in women previously treated for early stage breast cancer. CCGs should ensure that GPs are appropriately prescribing these agents once these guidelines are published.

5.6.4 Patients with serious mental illnesses and learning difficulties

Anecdotal evidence suggests that people with serious mental illnesses or learning difficulties are often diagnosed late, or in some cases not at all. Symptoms can be mistaken for being a result of their mental illness, so not taken seriously. This ultimately impacts on treatment and outcomes. However, we need a better understanding of the needs and experiences of these groups of patients to determine how to improve services.

Recommendation 48: NHS England should ask NIHR and research charities to explore the needs of people with serious mental illnesses or learning difficulties when they have cancer.

5.7 EARLY ACCESS TO PALLIATIVE CARE AND AHP SERVICES

Many patients would benefit from much earlier access to palliative support in their cancer treatment journey. However, palliative support is often considered secondary to the primary treatment course. Evidence shows that early referral to palliative care leads to better quality of life, reduced symptom burden, less exhaustive care, and lower costs[105]. It may result in patients choosing not to undergo more intensive treatment in some cases. For example, a pilot at the Christie Hospital has led to some patients choosing to forego chemotherapy if they have advanced incurable disease, in favour of starting palliative treatment earlier. The cost effectiveness and long-term outcomes of such approaches need to be evaluated.

Furthermore, many patients do not have sufficiently early access to AHP support. This support includes physiotherapy, occupational therapy, speech therapy, and/or dietary advice. Early access to rehabilitation advice can reduce acute visits to pain clinics, as well as enabling patients to return home more quickly after treatment.

Recommendation 49: NHS England should pilot, through new or existing vanguard sites, assessment of holistic needs for cancer patients at the point of diagnosis, evaluating the benefit of earlier palliative care and/or intervention from AHPs.

5.8 RESEARCH AND INNOVATION

The UK has a deserved reputation for creativity and excellence in the design and development of new interventions that have the potential to deliver significant improvements in outcomes. However, internationally we are viewed as being slower to adopt new innovations than other countries, other than in a few leading centres. This is the case even where those innovations are clearly cost-effective and/or were developed within the UK health system. It is also despite recent developments designed to address this such as the Cancer Drugs Fund and investment in advanced

[xxi] Research to be published imminently
[xxii] Ibid

radiotherapies such as IMRT and SABR. Slow adoption affects both the outcomes we achieve, and the attractiveness of England as a destination for inward R&D investment.

Continuous improvement in the quality of services being delivered to cancer patients depends on the accumulation of evidence from research studies undertaken in the UK and around the world. Some developments already under way could have major implications for demand and service configuration in the years ahead. In other areas, we will need to initiate research studies so that we generate an evidence base on which to make future decisions. Some of these areas are highlighted throughout this report.

5.8.1 Supportive environment for research

Research continues to be pivotal to developing our understanding and preventing, managing and curing cancer. It is at the heart of the progress we have seen in the doubling of cancer survival over the last 40 years. It will therefore remain essential if we are to continue driving improvements.

Participation in clinical cancer research has increased dramatically since 2001. This is largely due to the formation of the National Cancer Research Network (NCRN) and the National Institute for Health Research (NIHR). The UK is now world-leading in the number of cancer patients that participate in research - nearly 57,000 in 2012, representing 1 in 5 of all UK cancer patients[106]. There is strong evidence that patients who participate in clinical trials do better than those who do not. There is also emerging evidence that this benefit extends to all patients being treated in research-active settings, whether or not they are on trials themselves. Non-commercial trials bring added benefits in terms of leveraging free drugs for patients treated in the NHS, and identifying where treatment dose or duration can be reduced. These benefits are estimated at in excess of £40m a year for the NHS[107].
In addition to clinical trials, applied health research enables better understanding of how patient and clinician behaviours are associated with outcomes and enables the development and testing of patient-focused interventions. It will be important to continue to build capacity in this area.

Recommendation 50: NHS England should ensure commissioners and providers are incentivised to maintain the UK's world-leading position in cancer studies and applied health research. This should ensure that as many patients as possible have the opportunity to be part of a study, including in smaller stratified trials.

The regulatory and governance framework has been one of the main barriers to getting clinical studies up and running in the UK. The new EU Clinical Trials Regulation offers a real opportunity to reduce the time it takes to get studies set up. This will open up the prospect of additional clinical trials, particularly in rarer cancers and in younger people, if implemented appropriately. The Government and the MHRA, working with research charities, should continue to take a leading role in Europe to ensure that the new EU Clinical Trial Regulations are finalised and implemented as rapidly as possible.

Running trials in the NHS requires an agreement between research funders, the NIHR research network and NHS bodies to cover the various costs involved. The costs that the NHS covers - Excess Treatment Costs (ETCs) - are a critical component of clinical research. Without them, non-commercial funders would struggle to support the full costs of running trials. As well as providing the foundations for a research active NHS, ETCs can also leverage significant amounts of inward investment when non-commercial funders collaborate with industry. Currently there is no national policy on the commissioning of ETCs, which results in local level discussions with multiple providers and commissioners and consequent delays in setting up studies. On some occasions it means studies are unable to open in certain sites, depriving patients of access to trials.

For certain therapies it is essential that we take a national approach to meeting the ETCs of studies, to fit with national priorities. In cancer this is particularly relevant in radiotherapy, where we have already seen the benefit of national funding for SABR studies.

Recommendation 51: By the end of 2015, NHS England should publish clear guidance that commissioners must meet excess treatment costs for clinical trials

accepted on to the NIHR portfolio as part of routine business. ETCs for radiotherapy trials should be distributed through a national fund held by NHS England to ensure high quality clinical trials are developed and delivered optimally.

Recommendation 52: NHS England strongly encourage NIHR, research charities and other funders to ensure that relevant and effective patient and public involvement in research becomes the norm for research funders, funded applications and for grant applicants, in line with the overall drive to see a more patient-centred NHS.

5.8.2 Pull through of innovation

Faster adoption and dissemination of innovation would position the NHS in a more positive light. Our health service would be regarded as a system which harnesses excellence. It would also be seen as viewing innovation as a tool for delivering productivity and better outcomes, albeit sometimes with increased cost. Nowhere is this truer than in cancer. The Accelerated Access Review, chaired by Sir Hugh Taylor, has been set up to look at faster adoption of innovative drugs, devices, digital health and diagnostics for NHS patients. It aims to ensure that patients can benefit as quickly as possible from new discoveries, and will conclude at the end of 2015. An interim report will be published in late summer 2015.

The NCRI Clinical Studies Groups (CSGs) have an overview of all cancer clinical trials being carried out in the UK, and when they are likely to report results. They are able to assess which trial results will be practice-changing. The CSGs are also able to identify other process or practice changes which were not the primary focus of the trial but still might benefit patients and could be implemented more widely. It would be useful to develop a streamlined process through which such changes were incorporated as quickly as possible in to mainstream practice.

Recommendation 53: The NCRI Clinical Studies Groups, working with researchers and research funders, should develop a process by which all practice-changing conclusions that emerge from clinical trials conducted in the UK are channelled through to NICE and CRGs for incorporation into new clinical guidelines. They should also develop an early warning system for ground-breaking trials that are due to report.

6. HOW SHOULD WE IMPROVE EXPERIENCES OF CARE, TREATMENT AND SUPPORT?

Chapter Summary

- A cancer patient's experience of care is fundamental, from the point they first engage with the health service before their diagnosis, through to treatment and beyond
- The Cancer Patient Experience Survey continues to provide valuable insight. This should be commissioned annually and optimised through intelligent dissemination and linkage to other data
- Additional metrics should be developed and embedded in accountability systems alongside Cancer Patient Experience Survey data to drive continuous improvement
- Communication between cancer patients and staff in the health service needs to be improved. This will be facilitated through shifting the relationship between patients and staff, digital technologies and improving skills
- Patients should have access to all their test results and treatment records online
- Patients should feel empowered to be equal partners in decisions around their care

People diagnosed with cancer may require care and support at various stages of their cancer journey. This includes from diagnosis to initial treatment, living with and beyond cancer, through palliation and end of life. Interactions with the health service for those who have cancer will wax and wane depending on their needs, but are unlikely to comprise a 'one-off' experience. The support the NHS provides during and between experiences needs to be tailored to the individual. This is best achieved through meaningful engagement with patients and their carers to ensure services are responsive. The needs may be wide-ranging, including medical, practical, psychosocial and financial, and may require early and regular assessment, especially at key transition points. Delivering better patient experience will require a shift in the relationship between health and care professionals and patients, with more empowered patients able to make informed decisions about their treatment, care and support, and better able to self-manage.

6.1 MEASURING PATIENT EXPERIENCE

Overall, the majority of people with cancer receive good, compassionate care from the NHS. However, there have been parts of the NHS that have repeatedly compromised quality of care, including patient experience. These failings were highlighted in the Francis Report in its response to the Mid-Staffordshire care scandal[108]. The previous Government worked hard to respond to the Francis inquiry, seeking to transform many aspects of care and highlighting the importance of culture change.

However, there are still too many people with cancer who do not have a good experience of their care, treatment and support. For example, a quarter of all cancer patients will have treatment-related long term effects[109]. But only two thirds of cancer patients report that they felt the future side-effects of treatment were fully explained to them[110]. Overall Cancer Patient Experience Survey (CPES) satisfaction scores are high. However, patient experience falls below an acceptable standard in some areas. For example, some London hospitals are consistently in the lowest quintile of performers[11] (see Figure 20).

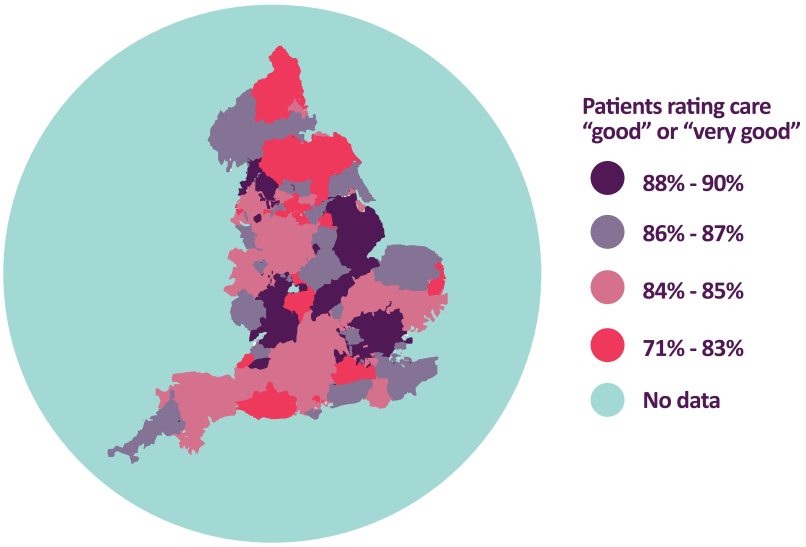


Figure 20: National Cancer Patient Experience Survey, 2014

There remain groups of patients who report worse experience than others including:

- lesbian, gay, bisexual and transgender communities
- black and minority ethnic communities
- younger patients
- those with some types of brain cancer
- patients diagnosed through emergency routes.

The 2014 CPES found that 1 in 5 cancer patients felt treated like a set of symptoms rather than being recognised as a person[11]. One in three didn't have confidence and trust in every ward nurse treating them[11].

According to CPES, only 1 in 3 patients are offered a conversation about research. Of these, 95 percent value having the conversation and 66% of those choose to participate in research. Of patients who report not having a conversation, 53% would value being asked. Patients who have had a conversation about research are more likely to report a high level of satisfaction with their overall care. Those who actually participate in research are even more likely to do so.

The CPES has proved effective at highlighting good and poor aspects of care. Patient experience data can add value at different levels – for performance management, accountability and service improvement, as well as to support reflective practice and to equip people affected by cancer with the information to drive change. For example, CPES has proven effective at encouraging hospitals to implement changes to improve results. In some cases, patient experience data may act as an early warning of emerging problems that will manifest much later in other measures such as survival. We therefore need to continue the measurement and monitoring of patient experience, and develop these measures further.

Although the CPES helps to highlight patient experience in acute settings, our understanding remains incomplete. The survey misses the experiences of patient groups who don't engage with it, such as some black and minority ethnic patients. It also fails to measure fully the experiences of cancer patients in primary and community settings. The survey could therefore be improved by taking advantage of opportunities for following up patients beyond the acute phase of their treatment and making better use of existing data by linking up datasets and identifying new ways to measure experience in key groups.

A particular challenge currently is that CPES cannot be used to survey children with cancer. The first national children's survey across the NHS has recently been published, providing an opportunity to understand better a methodology for measuring patient experience in this

group. It will be important to build on this to ensure we get the insights we need to improve services for children with cancer.

Recommendation 54: NHS England should continue to commission CPES annually. It should also take steps to increase BME representation in CPES for a minimum of 1 to 2 years to understand drivers of poorer experience within these groups better. It should consider how CPES data can be linked with other datasets to understand experience across the pathway. It should also develop a methodology to collect data on patient experience for under 16s.

6.2 INCENTIVISING CONTINUOUS IMPROVEMENT IN PATIENT EXPERIENCE

Improving people's experience needs to be prioritised across the pathway, including at the end of life. Often patient experience is not viewed as being on a par with the other elements of high-quality care (clinical effectiveness and safety). This is despite the fact that improving experience is intrinsically important to patients, and is also linked to improving other outcomes[111]. There needs to be a shift in the way patient experience is viewed, as a fundamental indicator of quality health care.

There is currently a disconnect between incentive systems and patient experience outcomes. The current best practice tariffs do not reflect cancer best practice outside a research setting, and do not take into account measures of patient experience. A number of approaches have been set out in the Dalton Review and FYFV which might assist in the transformation of the system of incentives and levers in cancer care. The NHS' ambition to shift attitudes so that patient experience has equal weight with other indicators needs to be embedded in how providers are assessed and incentivised.

While the CPES has driven improvements in some Trusts and across some areas, we must ensure that data is used in the most effective way to support ongoing improvement. Improving patient experience should be an aspiration for the whole of the NHS, not just cancer services. Indeed, cancer patients will have regular interactions with generalists or other members of the speciality workforce who should also provide compassionate and empathetic care.

Recommendation 55: NHS England should work with Monitor, the Trust Development Authority, the Care Quality Commission and partners to develop by 2017 a metric or set of metrics that would encourage providers and commissioners to focus more consistently on improving people's experiences of their care, treatment and support. Once developed, these measures should be rolled out nationally as part of the 'cancer dashboard' and embedded in incentives and mechanisms of accountability. For example, the CQC should incorporate these measures into its assessment metrics for hospitals.

6.3 STAFF EXPERIENCE

Research has shown that good staff experience contributes to better patient care[112]. There is a clear relationship between staff engagement and individual and organisational outcome measures, such as patient satisfaction, mortality and safety measures. The NHS regularly surveys its staff, with results informing local and national assessments of the quality and safety of care. We should enhance the role of staff experience measures in taking forward commitments to increase parity of esteem for patient experience metrics. Staff should be empowered to drive change in services and care, through tested solutions such as Schwarz Center Rounds and the Macmillan Values Based Standard. Providers should review the support currently provided to all NHS staff that have contact with people affected by cancer to ensure they have regular and meaningful appraisals and opportunities for reflective practice.

6.4 SHARED DECISION-MAKING

Shared decision-making is a process by which a patient is involved as an equal and active partner with the clinician in clarifying acceptable medical options and choosing a preferred course of care appropriate to the individual. Patients should leave consultations with clinicians feeling that any concerns have been heard and addressed,

with an understanding of what the clinician has communicated to them, fully prepared for the next phase of their journey. A successful conversation should be based on the following principles:

- The health professional gives a patient information about all the treatment options for the health problem, including research opportunities. They also give information about the option they would recommend as being the best medically, based on the patient's personal circumstances;
- The patient gives the professional information about their life and experiences of illness and treatment and whether one treatment and care option may fit better in their life than another. This preference may be different from the medically best treatment;
- The shared decision making conversation needs both the patient and the professional to understand the other's point of view. The conversation needs to agree the reasons why the decision made was the best one for the patient.

Cancer patients often feel their conversations are not in line with these principles. They don't obtain the information that is important to them about their diagnosis, treatment and care and don't feel confident in asking questions of their clinicians.

Shared decision making can be facilitated by providing decision aids, and support in using them. These aids help people think through the pros and cons of options, using question prompts to help people interact during consultations. NHS England already provides some decision aids online for selected groups of cancer patients[xxiii]. These need to be built upon and shared more widely with clinicians and patients.

Recommendation 56: NHS England, working through Clinical Reference Groups, and in partnership with charities, should develop on-line decision and communication aids for patients and carers to use with their clinicians. Where possible, these aids should be provided in the clinical setting for patients to access.

6.5 DIGITAL COMMUNICATION

Digital technologies offer opportunities to improve communication as well as drive efficiencies. More than two-thirds of the adult population now have smartphones[113]. The NHS could make better use of basic technologies, such as email, to enhance communication with patients.

Patients cite that they often have to repeat their story to different clinicians who don't have access to their records. They express frustration with the sporadic and sometimes impenetrable access to information about their diagnosis and treatment[110], or about research opportunities. Frequently, patients and clinicians decry time wasted in chasing test results and the need to schedule repeat appointments if these are not available. This is both bad for patient experience and a significant waste of NHS resources. Clinicians estimate that between 10 and 20% of investigations or appointments are repeated because they cannot access scans or pathology reports.

Patients should own their information, as an aid to efficiency and shared decision-making. They would benefit if all information shared with them during consultations was made available to them electronically. The NHS should take the opportunity offered by its world class cancer data to enable this. Online communication would not replace the interaction between clinical or nursing staff and the patient, and a cancer diagnosis would always be delivered in person.

Providing some information online should be the initial step in a journey that enables patients to manage their own records and care. Most of the focus of digital care record sharing to date has been on GP records. However, many of the interactions for cancer are in the secondary and tertiary sectors. Patient consent should be a pre-requisite to overcome information governance concerns.

Recommendation 57: From confirmation of a diagnosis, all consenting patients

[xxiii] http://sdm.rightcare.nhs.uk/pda/

should have the ability to access all test results and other communications involving secondary/tertiary care providers online. The aim should be to achieve this for all patients by 2020, extending to include all GP records thereafter.

Recommendation 58: NHS England should partner with charities or commercial partners in commissioning the development of a smartphone app which patients can use to collate all their diagnosis and treatment related information and correspondence in one place.

Cancer patients often express frustration with the fragmentation of their care. Some of the support patients need post-treatment is also required by people with other long-term conditions and many people with cancer will have one or more other morbidities. The NHS will be harnessing the potential of digital technologies over the next five years to support transformational delivery of care. Tools which enable care to be integrated around the person would be particularly beneficial. We would also encourage NHS England to consider the provision of free wi-fi within NHS premises to make it easier for patients and carers to access these digital tools and information.

Recommendation 59: NHS England should undertake a strategic review of how digital technologies might be used to drive improvements in patient experience, for example in the coordination of their care. This should include assessing how digital technology can be used to link to harder to reach groups.

6.6 WORKFORCE COMMUNICATION SKILLS

All staff who come into contact with cancer patients have a responsibility to ensure that every conversation they have with a patient delivers the information and support required. This is often despite restricted time and with challenging and complex messages to convey. Conversations are key – many patients describe being bombarded with confusing written information and signposting advice, while others receive none[110]. Most cancer patients highlight the value of conversations when they are done well. However too many patients feel that communication is not empathetic and offers no opportunity to query or discuss options. The CPES shows that a significant number of patients don't feel they are receiving the emotional support they need, with only two thirds of patients feeling they are able to discuss fears or worries[11].

Almost all staff within the health service will encounter people who have cancer. This emphasises the need for the entire workforce to have a better understanding of cancer, so that the burden of conversations doesn't lie solely with cancer specialists and so that opportunities to convey important messages are not missed. Clinical and nursing staff need the skills to be able to support open communication, hold difficult conversations and enable shared decision-making. Providers should be regularly reviewing the support provided to all NHS staff (including non-clinical staff) who have contact with people affected by cancer to ensure that they can access appropriate learning and development opportunities.

Recommendation 60: Health Education England should review the training and support currently provided to NHS staff. It should work with Medical Royal Colleges and other bodies to ensure that all new and, where appropriate, existing staff have mandatory communication skills training. This will need to include empathetic listening skills, shared decision-making, empowering patients to self-manage, and how to deliver difficult news.

6.7 ROLE OF CLINICAL NURSE SPECIALISTS

The CPES tells us that the support of a Clinical Nurse Specialist (CNS) is the most important contributing factor to people's positive experience of care. They play a crucial role in providing information, enabling communication and in coordinating care. The number of patients having access to a CNS has continued to increase from 84% in 2010 to 89% in 2014[11]. However, there is a shortage of CNSs and sometimes they are used inefficiently, for example, spending time on administrative tasks, rather than

providing specialist care.

As well as increasing the number of CNSs, the NHS should explore ways to deliver personalised care that is appropriate to the individual's level of need. Macmillan Cancer Support is undertaking a pilot of the role of Support Workers in a number of sites across the country. Early evidence suggests that these roles can undertake holistic needs assessments and provide the coordination of care that many patients state they need, from diagnosis through to living with beyond cancer. These roles can free up CNSs to concentrate on other activities. Alternative creative approaches are being trialled in East Kent and London, for example cancer patients having access to CNSs through a telephone helpline.

Recommendation 61: NHS England and the Trust Development Authority should encourage providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards, to guide them through treatment options and ensure they receive appropriate information and support. In parallel, NHS England and Health Education England should encourage providers to work with Macmillan Cancer Support and other charities to develop and evaluate the role of support workers in enabling more patient centred care to be provided.

6.8 CANCER SUPPORT GROUPS

Patients want to know what the best treatments are. They want to know where they can access specialist treatment for their specific cancer, and what is available to support them both during and post-treatment. This information is often not easily available. As a key part of personalised care, patients and carers should be able to obtain this information easily, and providers should work towards this aim. This is a particular challenge in cancer, with the myriad of problems a diagnosis can bring and the increasing number of co-morbidities patients are having to cope with.

Providers should maintain a directory of local services for people with cancer, their carers and families, and signpost to appropriate services. This directory should cover all types of cancer; people with rare and less common cancers in particular often report difficulties in accessing this kind of information. In many hospitals, this can be enhanced through active cancer support groups, which help facilitate and optimise access to this information.

Recommendation 62: NHS England should encourage all hospital providers to provide a directory of local services (electronic and on paper) and facilitate local cancer support groups (e.g. by providing free space), which can provide peer and signposting support to cancer patients being treated there. This should complement directories provided in general practice.

7. HOW SHOULD WE IMPROVE THE QUALITY OF LIFE OF PATIENTS AFTER TREATMENT AND AT THE END OF LIFE?

Chapter Summary

- Our understanding of the varying needs of people living with and beyond cancer means that we should now be providing services for patients that fully support them, with services tailored to the specific needs of each individual
- The Recovery Package and stratified follow up pathways have been developed to address these needs and should be rolled out as quickly as possible
- We need to measure the long-term quality of life for people living with and beyond cancer and develop a national metric to drive improvement
- The role of key stakeholders outside hospital settings is pivotal in improving the services provided to cancer patients. Care provided in the community and through primary care needs to be better integrated
- Cancer patients at the end of their lives are often not experiencing the care that they would choose. We need to provide appropriate integrated services for palliative and end of life care

7.1 LIVING WITH AND BEYOND CANCER

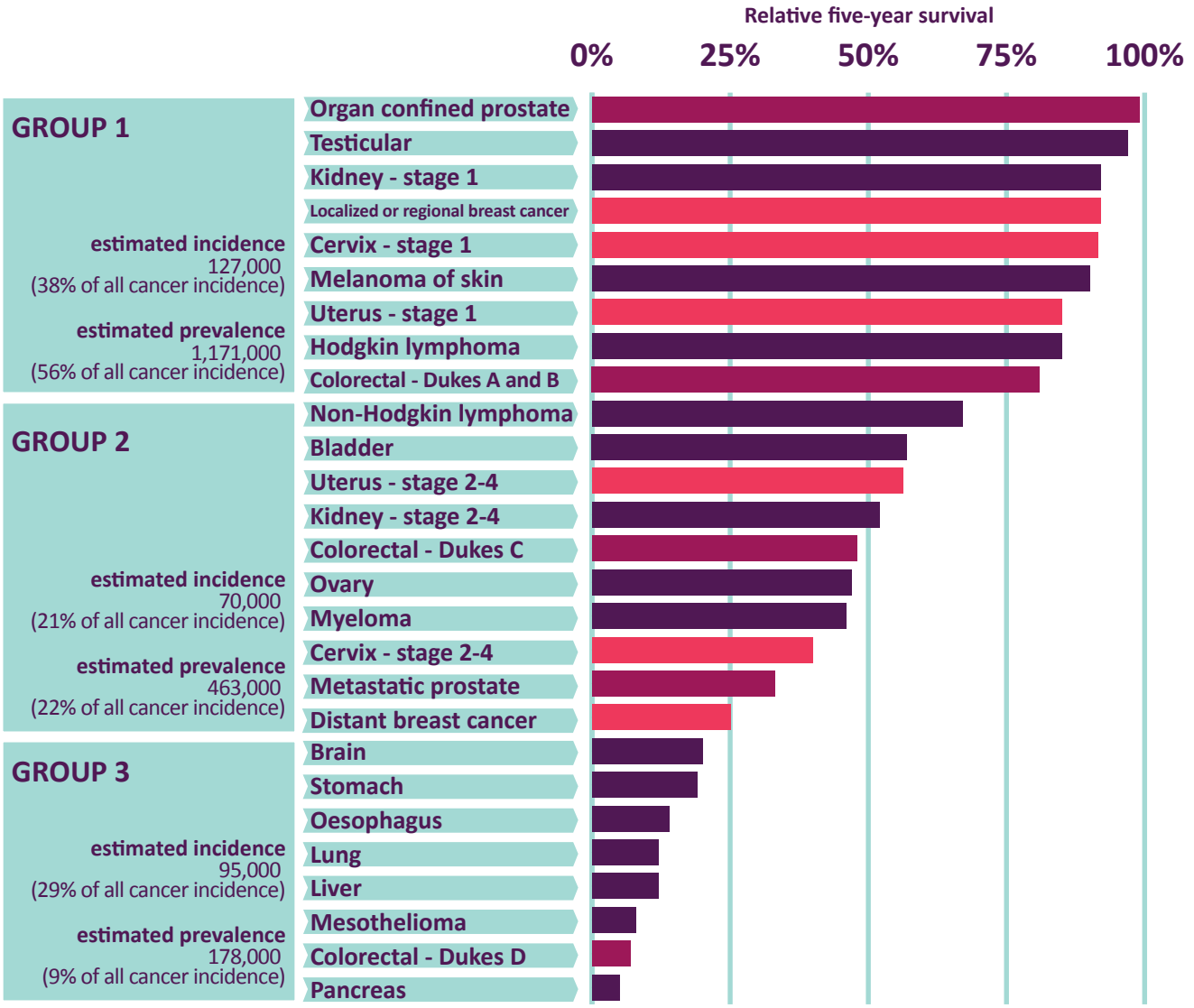
Though more people are surviving cancer, unfortunately this often doesn't mean living well. People living with cancer can have complex and very varied needs, many of which are currently not being met. One in four people who have been treated for cancer live with ill health or disability as a consequence of their treatment[109]. For example, around a fifth of patients treated for bowel cancer have ongoing problems with bowel control, more than half of patients treated for prostate cancer suffer from erectile dysfunction and a further 38% from urinary incontinence[xxiv]. Cancer can affect all areas of a person's life, including relationships, work, and finances – 83% of people say they are financially impacted by cancer.

We need to support people with cancer to return to as good a quality of life as possible after active treatment has ended, or support them to achieve their personal goals if they will be living with either primary or secondary cancer for some time. People require holistic support from diagnosis onwards, encompassing their physical, financial, psychosocial, and information and support needs, throughout their entire cancer journey. Care should be built around what matters to the person, and individuals should feel prepared for the life consequences of their cancer and its treatment, equipped to manage their care and with control over their life as a whole. Managing the consequences of treatment needs to be a key focus, particularly for people with intermediate and long-term survival.

With more people living with and beyond cancer, it is important that we have a good understanding of their different outcomes and needs to inform the design of support services and stratified pathways. Macmillan Cancer Support[xxv] has developed a model based on average five year survival. This points towards how longer-term support can be tailored to meet people's needs better. For example, much could be learnt from the support of people with other long-term conditions in relation to supporting many of the people in group 2 in Figure 21. We need to be supporting people in different ways. Continuing as we are is not sustainable, nor will it meet people's needs holistically.

[xxiv] Sometimes, these long-term effects can be ameliorated through earlier intervention – see section 5.7

[xxv] The researchers recognise that better data collection, analysis by stage and further segmentation need to be progressed as a priority to develop and refine the model. We must also take into account the significant variation in people's cancer journeys within cancer types and how this links to people's needs and to service design.



Note: McConnell H, White R, Maher J. *Understanding variations: Outcomes for people diagnosed with cancer and implications for service provision.* 2014. European Network of Cancer Registries Scientific Meeting and General Assembly

Data quality of survival rates:

- England-wide data based on patient diagnosed after 2005
- England-wide data based on patient diagnosed before 2005
- Regional data, non-UK data or review articles. For this category we have not provided data labels as the data is not of sufficient quality to report the number

We have excluded leukaemia, head and neck cancer, ill-defined and some rarer cancers in the categories as they are difficult to stratify as the cancer pathways are highly diverse.

Figure 21: Stratified outcomes for people diagnosed with cancer

Recommendation 63: The NHS and partners should drive forward a programme of work to ensure that people living with and beyond cancer are fully supported and their needs are met. This should include approaches to reducing and managing long-term consequences of treatment. This could include understanding how tested approaches such as trigger questions can be embedded into clinical practice, as well as approaches to ensuring that specialist services for complex problems arising from cancer treatment are commissioned.

7.2 MEASURING QUALITY OF LIFE

A strong focus on supporting people living with and beyond cancer is required if we are to meet their changing needs. As yet we do not have a reliable set of metrics for measuring long-term quality of life. The Department of Health has previously worked with Macmillan Cancer Support to pilot a set of Patient Reported Outcome Measures (PROMs) and the learnings from this can be built upon to create a national metric for quality of life for people living with and beyond cancer[114]. The metric should be suitable for use at various levels of the system, including by commissioners and providers.

Recommendation 64: NHS England and Public Health England should work with charities, patients and carers to develop a national metric on quality of life by 2017 which would enable better evaluation of long-term quality of life after treatment. PROMs should be rolled out across breast, colorectal and prostate cancer by 2020, with evaluation informing further rollout across other cancer types.

7.3 COMMISSIONING SERVICES FOR PEOPLE LIVING WITH AND BEYOND CANCER

Better support for people after treatment can deliver significant benefits in terms of improved quality of life. It can also encourage behaviours that are more likely to prevent recurrence or acute presentations back to the health service with late consequences of treatment. For example, there is strong evidence that patients who are encouraged to undertake a programme of physical activity post-treatment suffer from reduced levels of fatigue and have overall higher quality of life, across a range of cancer types[115, 116]. However, most patients are not given advice on exercise, and they need to be supported to make lifestyle changes.

Some progress has been made in developing interventions to support people living with and beyond cancer. But much more needs to be done. The National Cancer Survivorship Initiative (NCSI), which ran from 2008 to 2013, developed a case for change[48] and identified priority areas for focus. The Living With and Beyond Cancer Programme (a two year programme of work) has taken this forward, seeking to embed these priority areas into commissioning and practice. We now need to accelerate the pace of change across the health and social care system, by strengthening national and local leadership, setting national service specifications and rolling out tested solutions.

The Recovery Package is a combination of different interventions, which when delivered together, can greatly improve the outcomes and coordination of care, including better and earlier identification of consequences of treatment. It has been developed and tested through the NCSI to assist people living with a diagnosis of cancer to prepare for the future, identify their individual needs and support them to live well after treatment.

Recommendation 65: NHS England should accelerate the commissioning of services for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020. In addition, NHS England should work with NICE to develop a guideline, by mid 2016, for a minimum service specification, building on the Recovery Package, thereafter to be commissioned locally for all patients, together with a suite of metrics to monitor performance. This specification would be expected to evolve over time, as resources permit. Initially this specification could include the following elements:

- **A holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agreed with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co-morbidities.**
- **Information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years.**
- **Potential markers of recurrence/ secondary cancers and information on what to do in these circumstances.**
- **Key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.**
- **A cancer care review to discuss ongoing needs and completed by the patient's GP or practice nurse.**
- **A treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP.**
- **Access to a patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person**

for the transition to supported self-management, including advice on healthy lifestyle and physical activity.

- **Signposting to rehabilitation, work and financial support services.**

Children, teenagers and young adults have specific post-treatment requirements which overlap with but may be different to adults. These need to be appropriately commissioned and delivered. Transition points are often particularly poorly managed, not least as treatment can often be delivered a long way from home. Age-specific support will need to be determined for these patients, and some specific psychosocial and/or keyworker services maybe provided by specialist charities, for example, Clic Sargent or Teenage Cancer Trust. NHS England should ask the CTYA CRG to feed into the NICE guideline living with and beyond service requirements for the CTYA populations.

In addition, 7 in every 10 people treated for cancer have at least one other long-term condition and nearly a third have three or more such conditions. However, we do not have a good understanding of how multiple morbidities affect cancer patients.

Recommendation 66: NHS England should ask NIHR and research charities to develop research protocols which would deliver better understanding of the prevalence and incidence of multi morbidities and the effects these have on outcomes and quality of life.

7.4 FOLLOW-UP PATHWAYS

A large proportion of current NHS cancer costs relate to treating people who are in the survivorship phase, when initial treatment has finished[117] (see Figure 22). More tailored care in this phase has the potential to reduce costs through reducing recurrences, better managing side-effects and supporting people to live well.

Stratified follow-up pathways – which comprise needs assessment, support for patients to self-manage, remote monitoring and re-entry pathways – can offer a more effective approach to aftercare than traditional medical models of follow-up. There is evidence in breast and colorectal cancer that stratified follow-up pathways deliver improved quality of care, at worst on a cost-neutral basis. For example, a pilot in Northern Ireland supported by Macmillan Cancer Support, has shown the potential for

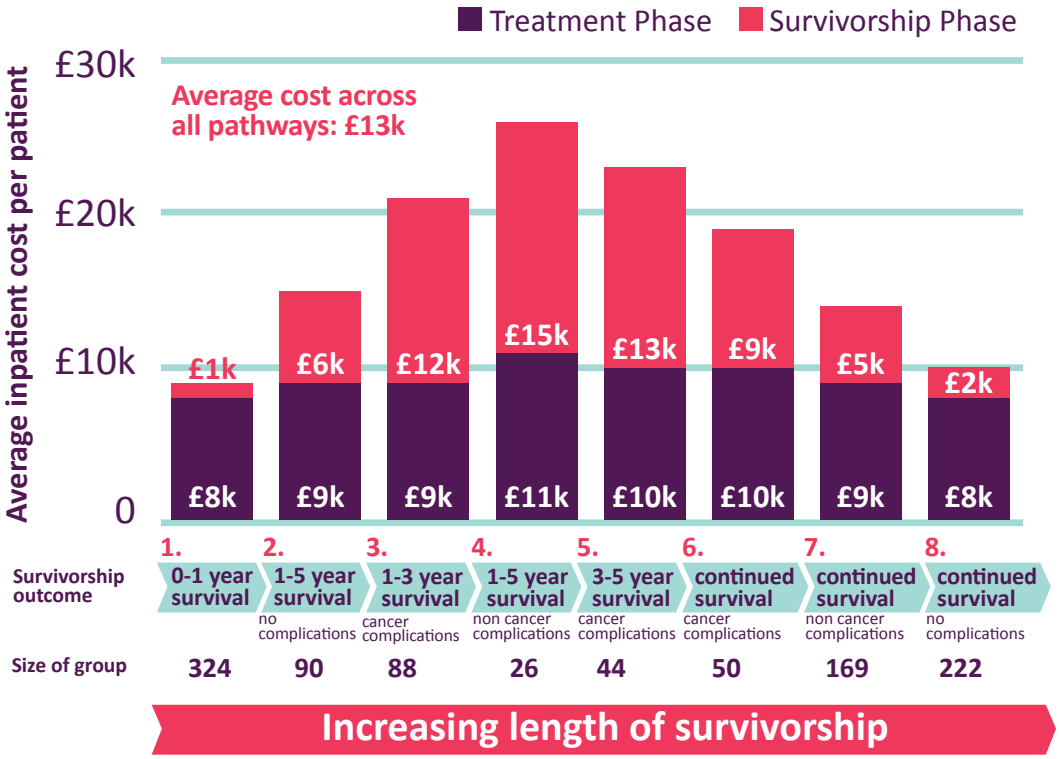


Figure 22: Costs associated with different survivorship pathways[117]

stratified follow-up pathways to obviate the need for thousands of out-patient appointments[118xxvi]. However, other than in early breast cancer, optimal models still need to be designed and properly cost-evaluated before national roll-out. Ultimately, any pathways will need to be tailored in line with local needs.

Recommendation 67: The Trust Development Authority and NHS England should ensure all providers are incentivised to start implementing stratified follow-up pathways of care for patients treated for breast cancer. NHS England should pilot stratified follow-up pathways of care for other tumour types, ideally including prostate and colorectal and some rarer cancer types, with an aim to roll out nationally for at least two other cancer types by 2020.

Recommendation 68: NHS England, via the National Cancer Team (see section 8), should define a set of research priorities to be considered by NIHR and other research funders, on long-term patient needs and survivorship issues, and identify mechanisms to enable this research to happen.

Recommendation 69: NHS England should ask NIHR and research charities to develop research protocols which would lead to a much better understanding of the long-term consequences of different treatment options, including patient experience and quality of life considerations.

7.5 CANCER REHABILITATION

Rehabilitation aims to restore a person's roles and functions as far as possible, and help them to adjust to limitations where required. These roles and functions may be relevant to any context, including family, society or work[119]. Effective rehabilitation is vital in minimising consequences of treatment and improving quality of life for someone with cancer. Preventative rehabilitation delivered before and during cancer treatment also has the potential to reduce the future clinical and non-clinical needs of a person with cancer. This could, in turn, reduce the cost to the health and social care system associated with later stage and more serious interventions. However, rehabilitation is not yet embedded across the cancer pathway. There are variations in access to allied health professionals who deliver rehabilitation services. AHPs are commonly part of multi-disciplinary palliative care teams, but not always part of multi-disciplinary teams before the palliative stage.

Recommendation 70: NHS England and Health Education England should support a national review of the cancer rehabilitation workforce and promote the role of AHPs in multi-disciplinary teams.

7.6 DEPRESSION

Depression and anxiety are very common complications of cancer and its treatment. These are often transient reactions. However, they develop into a depressive disorder of clinical severity called major depression in around 10% of patients[120]. Major depression has serious adverse effects on patients with cancer. It reduces patients' quality of life by increasing symptom burden and decreasing physical and social functioning. It may impair adherence to anticancer treatments and thereby reduce survival and it impedes a return to normal living after effective cancer treatment. The majority of depressed cancer patients do not currently receive adequate treatment. Consequently, the outcome of depression is poor for such patients, even when the cancer team is informed of the diagnosis. The common practice of leaving treatment to primary care or mental health services is ineffective. Better management of depression could greatly improve patient outcomes.

There are two main reasons that depressed cancer patients do not receive adequate treatment. First, the depression is often not detected. Second, effective treatment is not provided. Integrating depression care into cancer care can overcome these barriers to effective management and achieve 'parity of esteem' for patients' mental and physical needs. The failure to detect depression in

[xxvi]The N Ireland pilot was evaluated by PWC and showed that 58% of breast cancer patients could self-manage, with rapid access back into the system if necessary; 3,000 outpatient appointments were freed up.

cancer patients can be overcome by screening. But screening is only useful if linked to an effective treatment program. Depression in cancer patients can be treated by medication and by psychological treatment. These treatments are most effectively and efficiently delivered using a systematic collaborative care model, such as "Depression Care for People with Cancer" (DCPC). This is a team-delivered system of care in which a psychiatrist supervises specially trained cancer nurses who see the patient and work in collaboration with primary care to deliver and monitor treatment.

A recent large randomised trial of DCPC found that it substantially reduced depression and improved quality of life when compared with usual care[121]. DCPC is highly cost-effective, with a cost per QALY of £9,500. Modelling of a combined screening and treatment system indicates that a depression management system including both components is highly likely to be cost-effective at NICE thresholds when compared with usual care.

Recommendation 71: NHS England should consider piloting, through new or existing vanguard sites, the commissioning of integrated evidence-based depression care that includes screening and treatment systems.

7.7 PROVISION OF CARE IN THE COMMUNITY

Through engagement with patients in the development of this strategy we have heard that not enough support is given in managing the consequences of treatment. Many feel unsure where to seek help outside secondary care. There is emerging evidence that providing services to support patients within the community can be cost-effective through preventing emergency readmissions and less intensive use of acute resources[122]. For example, in London, a community oncology nursing service, managed and provided through the tertiary care hospital, supports patients to manage their condition post initial treatment. This pilot has shown early evidence of improving patient experience, reducing emergency re-admissions and improving treatment adherence for oral chemotherapy, as well as saving costs overall.

Recommendation 72: NHS England should evaluate, through new or existing vanguards, whether the establishment of community oncology nurse services and community pharmacy services could cost-effectively assist with management of consequences of treatment and treatment adherence.

Cancer is not the only condition where survival has dramatically improved and people are now living long-term with the consequences of their condition or treatment. Many of the services that would benefit those living with cancer would also benefit those with other long-term conditions. Furthermore, our cities, towns and villages can be designed and developed in ways which promote a sense of wellbeing and liveability through integrated physical and social assets and infrastructure. This approach enables organisations to support residents living with and beyond cancer from becoming isolated or trapped within a narrow home, work or family environment.

Recommendation 73: CCGs and HWBs should work to identify and promote best practice in approaches to support people living with and beyond cancer. They should involve individuals and organisations beyond the NHS, for example employers, community organisations, and charities.

7.8 SUPPORTING PEOPLE WITH CANCER TO RETURN TO WORK

Work is as important for people with cancer as everyone else. As well as the financial and social benefits of being in work, there is strong evidence that good work has a positive impact on people's health and recovery. However, people with cancer are currently 1.4 times more likely to be unemployed than the general population[123] and many struggle with little or no co-ordinated support to remain in work following treatment[124]. With cancer survival rates improving and people living and working longer, the number of working lives affected is set to increase from the current figure of 750,000 to an estimated 1.7 million by 2030[10]. Macmillan Cancer Support and

other charities have worked with a number of local authorities and employers to pilot schemes which assist people who have had cancer in returning to work. Return to work plans need to be fully integrated into care planning to encourage the commissioning of vocational rehabilitation services.

Recommendation 74: NHS England should work with partners to ensure that supporting people with cancer to return to work is a key focus. This should include ensuring that return to work is fully integrated into assessment and care planning and should encourage the commissioning of vocational rehabilitation services.

7.9 END OF LIFE AND PALLIATIVE CARE

Unfortunately a significant number of people diagnosed with cancer die from their condition. Cancer causes more than a quarter of all deaths in England and Wales. Although the age-standardised mortality rate is falling, absolute mortality is expected to increase due to the growing population.

Little is known about the experience and quality of care for those at the end of their lives, but the evidence we do have shows that people are not experiencing the care that they would choose. Of those who stated that the individual had a preference, nearly three in four (73%) respondents said that this was to die at home[14], but fewer than a third (30%) of cancer deaths are at home[125]; indeed 53% still die in an NHS hospital[14]. Round the clock community nursing and out-of-hours access to other services play an important role in reducing unnecessary emergency admission. Without them, people are often unable to die at home in line with their wishes[13]. Provision at present is patchy, not least as there are gaps in the community workforce. For example the past decade has seen a 47% reduction in the number of qualified district nursing staff in England. This is expected to worsen, with over a third (35%) being over 50 years old and coming up to retirement age[126]. Providing more coordinated care in the community, closer to people's homes, would result in better outcomes for people.

Progression towards end of life for cancer patients is often more stable and predictable than other conditions. Cancer is therefore a unique test bed for end of life care. It should be a core principle that people nearing the end of their life[xxvii] should be supported to make decisions, manage their care and live well until they die. Their care should be coordinated and planned to ensure they die in the place and in the way they have chosen. Their families and carers should have the opportunity to prepare for death and should have access to practical and emotional support.

Proper provision of end of life care services can be highly cost-effective. The End of Life Care Intelligence Network suggests there is a potential saving of £958 for every person who dies in the community rather than in hospital[127].

There are defined elements which would make the most difference to people in terms of the care they experience[128]. These include good early care planning which is tailored to people's needs and preferences at the end of life, coupled with systems which allow these plans to be shared with people involved in the individual's care. Advance care planning in particular can be used to establish a person's wishes about their care at the end of life and this increases the likelihood of their wishes being met[128]. The rollout of the Summary Care Record provides the opportunity for everyone to digitally record their preference for place of death. A frequent reason for late end of life care planning appears to be inadequate clinician communication skills or an unwillingness to initiate conversations about death. A Dying Matters pilot study found that 60% of GPs rated themselves either 'not confident' or 'not very confident' in initiating conversations about end of life. The Gold Standards Framework can be used in GP practices to identify and risk stratify patients on the basis of need. It can help practices identify the 1% of patients who are likely to die within a 12 month time frame (most of whom will have cancer as a primary diagnosis).

[xxvii] The Palliative Care Funding Review treats end of life as a transition point when curative treatment is no longer deemed appropriate or not chosen. Healthcare professionals in England tend to define it as the last year of life. Others take a broader view as beginning from the point of a diagnosis that cancer is incurable but treatable.

What's important to me: A review of Choice in End of Life Care (the Choice Review) sets a blueprint for how greater choice in end of life care can be achieved. The Choice Review outlined the need for better coordinated care: early identification, joined up services and systems, care planning, shared care records, integrated IT systems (such as Electronic Palliative Care Coordination Systems,), better coordination and communication between health and social care professionals, community services, and family involvement. This report endorses these recommendations. There is now a real opportunity to transform end of life care to ensure that everyone has a named senior clinician responsible for their care and preferences and their own care coordinator.

The Choice Review showed that in end of life care many people would see place of care and death as the most important choice to them, with others prioritising other choices such as levels of pain management. Only 39% of respondents to the 2013 National Survey of Bereaved People said that pain was relieved "completely all the time" during the final hospital admission[14]. Less than a quarter reported that people with cancer had their pain relieved "completely, all the time" while at home in the last three months of life[14]. This compares with nearly two-thirds (62%) of those who died in a hospice who experience complete, continuous pain relief. In hospitals and care homes the effectiveness of pain relief was similar across cancer, CVD and other causes[14]. Community nurses provide vital medical support and pain relief which would otherwise have to be provided within hospital. Yet access to these services in the community at all times of the day or night remains highly variable for people who wish to be cared for and die at home.

Recommendation 75: NHS England should ensure that CCGs commission appropriate integrated services for palliative and end of life care, in line with the NICE Quality Standard (2011). They should take into account the independent Choice Review and the forthcoming Ambitions for End of Life Care, working with Health and Wellbeing Boards. They should consider the role of the 'Gold Standards Framework' within their delegated powers for commissioning of primary care. CQC should incorporate end-of-life care into its assessment metrics for hospitals and other providers of cancer services.

8. HOW SHOULD WE IMPROVE THE EFFICIENCY AND EFFECTIVENESS OF DELIVERY AND DRIVE IMPLEMENTATION?

Chapter Summary

- The cancer pathway is complex with a mix of cancer types, a constantly evolving evidence base, and engagement across a number of services from primary through to tertiary care. There are also interactions throughout the pathway with social care and community services
- Integrated Cancer Alliances should be established at the sub-regional level to develop integrated care and treatment pathways, and address variation
- There needs to be greater clarity as to which commissioning decisions should be taken at different levels, how commissioners and providers should be supported to continuously improve, and how this will be evaluated
- Good quality cancer care will only be provided with an appropriately resourced workforce. We have outlined areas that have severe shortfalls and opportunities to make more efficient use of resources through skills mix and networks
- The commitments in this strategy will rely on high-quality and, in many instances, near real-time, cancer intelligence capability
- We will need strong national leadership supported by sufficient resource to drive these proposals forward, in the form of a National Cancer Team

This report has set out a number of recommendations to drive significant improvements in cancer outcomes over the next 5 years. Achieving these will require reform in how cancer care is currently delivered. These reforms will include changes to commissioning arrangements, better alignment of financial flows and exploration of new models of care. The current system of payment and incentives does not provide for transformation in the structure and organisation of the delivery of cancer services. Neither does it incentivise innovation and fast roll out of new service models and technology.

Current commissioning arrangements, combined with tightening budgets, have led to fragmentation and a loss of momentum in transforming cancer services[129]. There has been a loss of local leadership and infrastructure, leading to variation across organisations in their approach. We need to re-build relationships and inject cancer-specific resource and expertise into local health economies and redesign the accountability framework. Ideally:

- NICE, CRGs and others should set clear standards for different aspects of cancer care
- Commissioners (CCGs and NHSE) should purchase services which deliver to these standards
- Providers and professionals should deliver what is commissioned to these standards
- Regulators (Monitor, TDA, CQC, GMC, etc) should ensure that commissioners, providers and professionals are delivering to these standards
- Patients and the public (supported by charities where appropriate) should provide external accountability by championing the need for higher standards and better delivery. They should highlight examples of good and poor quality care.

8.1 COMMISSIONING

Currently, commissioning is undertaken by NHS England and CCGs. Clinical Reference Groups also act as a source of clinical advice for the commissioning of specialised services. There are 211 CCGs serving a median population size of around 250,000 people. CCGs commission services for the majority of common cancers (excluding radiotherapy, chemotherapy and specialist interventions). NHS England commissions care from specialist centres for rarer cancers, specified interventions, specialist surgery for some common cancers, chemotherapy and radiotherapy. NHS England's responsibilities are discharged through four regional teams. Diagnostic services have historically been commissioned through block contracts with providers.

Until recently, NHS England has directly commissioned primary care, although this is currently in transition. CCGs are now able to take on delegated commissioning of general practice. The approach that CCGs can take spans three levels of involvement from minimal through to fully delegated powers. Robust governance arrangements are put in place via 'joint commissioning boards', which will have lay membership and representation from GPs in the CCG locality as well as public health and secondary care consultants.

In different parts of the country, Strategic Clinical Networks and Clinical Senates also advise on cancer commissioning to a greater or lesser extent. Furthermore, a number of services critical to cancer are also provided through Public Health England, as described earlier.

Providers, professionals and commissioners agree that cancer services would benefit from greater strategic coherence in commissioning. The current complexity of local and specialist commissioning is seen as confusing and hampers efforts to take a 'whole pathway' and 'whole person' approach to service redesign. Broad support remains for the role of specialised commissioning of many cancer services. However there is a desire to take forward more flexible models for commissioning as outlined in the Five Year Forward View.

It is not feasible or desirable to commission all cancer-related services through one body given the current structure of the NHS. It is therefore appropriate to consider a set of principles that guide the commissioning of different services at different levels. We would propose these should be:

- **Expertise of commissioners** – it is difficult to become an expert in aspects of commissioning which only affect small numbers of the resident population. We suggest that a "rule of thumb" might be four procedures per week, i.e. 200 per year.

- **Improved outcomes for patients** – there is strong evidence for increased centralisation of complex services, such as some surgery, radiotherapy and chemotherapy. There is equally a patient "pull" and a need to integrate with other locally-provided services that drives for decentralisation of others such as access to diagnostics, rehabilitation, end of life care, and some types of "safe" chemotherapy.

- The need to get **best value for money**.

- The need for **adequate volumes of patients** to be able to monitor outcomes appropriately.

In cancer, most elements of treatment need to be commissioned at population levels greater than those served by CCGs. This therefore requires coordination across CCGs. For example, most cancer surgical techniques are provided to a small number of patients, and are complex, and so should be commissioned across larger populations. The exceptions to this are surgery for breast and colorectal cancers. Approximately 200 cancer patients per CCG will require surgery for primary breast cancer each year, and around 100 will require colorectal cancer surgery. However, colorectal surgery is also required for a large number of non-cancer patients and is therefore appropriate to be commissioned at CCG level and provided in most District General Hospitals (DGHs). Diagnostic services and post-treatment services will be needed by large numbers of patients, including many patients without cancer. These services are therefore appropriate to be commissioned at CCG level. We expect that expansion of "Section 75 co-commissioning" (joint commissioning

by CCGs and local authorities) will facilitate better coordination of cancer services at the local level.

Recommendation 76: By the end of 2015 NHS England should set out clear expectations for commissioning of cancer services. All commissioners should commission to NICE guidelines and CRG-approved service specifications as a minimum. The following principles should form the basis of the new cancer commissioning landscape, to be clearly defined in national guidance from NHS England (see Figure 23):

- **All treatment services for rare cancers (fewer than 500 cases per annum across England, including all paediatric, teenage and young adult services) should be commissioned nationally.**
- **Other cancer treatment services (cancer surgery where national volumes are less than 2,500 per year, all remaining radiotherapy, and all remaining chemotherapy) should be commissioned by a lead commissioner across populations of 4-5 million or more.**
- **Cancer surgery where national volumes are between 2500 and 7500 per year should be commissioned by a lead CCG commissioner for populations of 1-2 million or more.**
- **Breast and colorectal cancer surgery should be commissioned at CCG level.**
- **Diagnostic services to confirm or exclude cancer should be commissioned at CCG level, including a range of blood tests, chest x-ray, ultrasound, CT, MRI, endoscopy and biopsy.**
- **Primary care services should be commissioned by NHS England Regional Teams or through CCGs via delegated responsibility where appropriate.**
- **Services to support living with and beyond cancer, including end of life care, should be commissioned by CCGs with support from HWBs.**

The model we have set out for commissioning in section 8.1 will move us forward significantly. It will mean better coordination of the services we are providing for our patients. However, there is an opportunity to go further and truly bring together all elements of the cancer pathway.

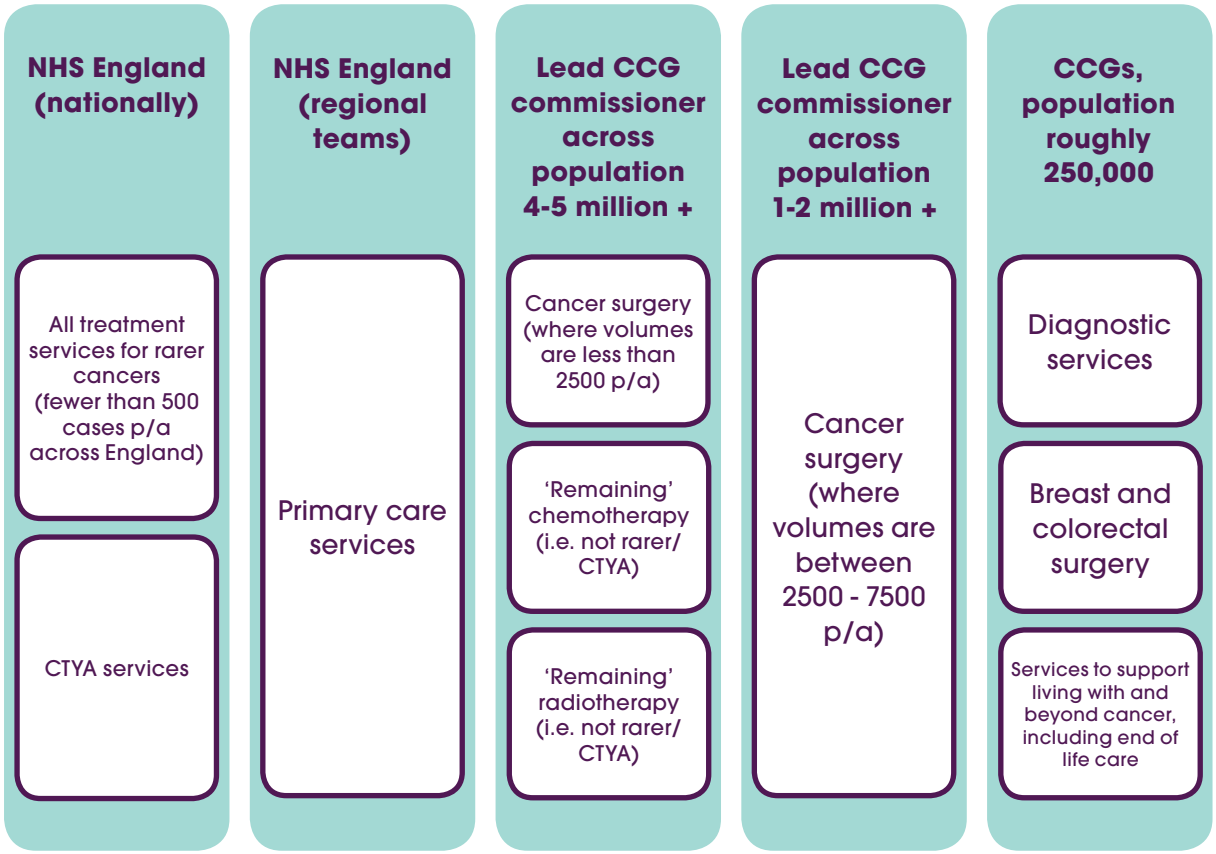


Figure 23: Proposed commissioning of cancer services

The benefits of doing this would be to break down siloed approaches to budgets and planning. This would allow more optimal pathways for patients, and the realisation of savings in certain parts of the pathway. It could potentially unlock system blockages and enable re-investment of savings to further improve outcomes.

The NHS is already exploring new models of care that could transform how we commission and deliver services[130]. There is a need to consider how financial incentives will operate when commissioning an entire cancer pathway. A population-based budget approach involves building up the funding model for a defined target population and identifying the funding required from modelling the range of service needs.

Recommendation 77: NHS England should work with Monitor to pilot the commissioning of the entire cancer pathway in at least one area. Ultimately, this should include investigation, through diagnosis and treatment, living with and beyond cancer, and end of life care. The pilot should test a fully devolved budget for that population, to be delivered over multiple years. Commissioning of services should be based on a pre-specified set of clinical and patient experience outcomes.

There need to be appropriate incentives and reimbursement mechanisms in place for the system to support continuous improvement in cancer outcomes. National Prices in tariffs are largely based on the national average costs of delivering patient activity. However, cancer care is more complex in general and therefore more costly than standard acute care. Independent studies[131] have demonstrated that national tariffs underestimate true cancer treatment costs by around 20% on average. This means that cancer care may be underfunded as a whole. As cancer prevalence increases, this funding gap is likely to widen. Some elements of recognised best practice are not reimbursed under the national payment system but are expected to be covered by payments for outpatients, despite these outpatient tariffs sometimes being insufficient to cover these aspects. Nationally, Monitor and NHS England are looking to move away from traditional activity based payment systems and are considering a number of new payment approaches[132]. Although these are not only being considered for cancer care, elements of these approaches may be appropriate to incentivise care in the right setting if priced correctly.

National tariff is revised annually. However, it is at best a 2-3 year process to adjust the prices set out in the tariff to reflect changes in underlying cost, which can be inappropriate in a set of diseases such as cancer, where treatment is advancing rapidly. For example, within radiotherapy, we have heard that current tariff structures disincentivise modern optimal treatment pathways[133]. Since it will not be possible to change coding in the short-term, while Monitor and NHS England undertake more fundamental reform of the payment architecture, it is suggested that changing the definitions or "currencies" within the existing tariff structure might be able to deliver some short-term wins. Over the next 6 months, Clinical Reference Groups should advise NHS England and Monitor whether adjustments to the definitions of certain treatment tariffs would deliver a more efficient use of resources for 2017/18, within the existing overall treatment budget.

8.2 LOCAL IMPROVEMENT ARCHITECTURE

Providers and commissioners need to work together to deliver joined up pathways and high quality cancer services across populations. Many patients' cancer treatment pathways involve a transfer between different providers of care, in both the acute sector and the community. Providers should work together to ensure that these transfers do not cause delays for patients, nor a break in the continuity of their care. They can do this by ensuring prompt electronic data transfers, clear arrangements regarding key worker support, and by monitoring the time course of these care pathways. This can be facilitated through Cancer Alliances. At a minimum, the following functions should be carried out in every local health economy:

- Sharing best practice, innovation, and learning
- Identifying and addressing variation
- Identifying links to new models of care and radical transformation
- Integrating care along pathways, across

health and social care, and across primary, secondary, and acute care, including inter-hospital transfers
- Monitoring performance across the local health economy
- Supporting providers with performance issues
- Involving users in coproduction of local cancer services

There are a number of organisations at national, regional and local level that support CCGs and link to providers. Twelve Clinical Networks (previously known as Strategic Clinical Networks) focus on priority service areas (including cancer) to improve equity and quality of care and health outcomes for their population. They bring together those who use, provide and commission services to support effective delivery. However, the current model for local improvement is unable to support cancer services adequately. There is far too much variation across the country in what each organisation is responsible for, and how they are delivering. Commissioners report that cancer commissioning is too disjointed. It is also clear that Network resource dedicated to cancer is insufficient.

Recommendation 78: NHS England should set expectations for and establish a new model for integrated Cancer Alliances at sub-regional level as owners of local metrics and the main vehicles for local service improvement and accountability in cancer. We advise that Cancer Alliances should be co-terminus with the boundaries of Academic Health Science Networks (AHSNs), although in some large AHSN geographies there may be a need for two Alliances. Alliances should be properly resourced and should draw together CCGs and encourage bimonthly dialogue with providers to oversee key metrics, address variation and ensure effective integration and optimisation of treatment and care pathways. Cancer Alliances should include local patients and carers, nurses and Allied Health Professionals.

Discussions through the development of this strategy have indicated an optimal population coverage of 2-3 million for a Cancer Alliance. Patient involvement in Alliances could be supported by local or national charities. Cancer Alliances will need to receive regular up-to-date intelligence on the dashboard of performance metrics from NCIN. They should have the authority to request CCGs to undertake root cause analysis of deficits in services, for example where a high proportion of patients are diagnosed through emergency presentations. Cancer Alliances should be accountable to the National Cancer Team (see section 8.7).

8.3 NATIONAL QUALITY STANDARDS

Addressing variation in the quality of services will be pivotal to delivering the improvements in outcomes envisaged in this strategy. This is best achieved if there is consensus and clear standards for what good care looks like. The NHS has a duty to deliver the best standard of care based on the latest evidence base. The role of NICE in developing evidence-based guidelines therefore remains essential. However, clinical experts within the NHS need to take more of a leading role in shaping the agenda for NICE, to ensure that new evidence on interventions and care pathways is considered in a timely manner as it emerges. Unfortunately some NICE guidelines, for example around minimum volumes for cancer surgery, have not been revised for ten years or more and are no longer considered fit for purpose. This means that commissioners and providers operate with different expectations, making the problem of variation worse.

As a minimum, guidelines should be updated every 2-3 years for most types of cancer. One of the considerations in updating the guidelines should be to ensure that they are patient-focused and holistic. In addition, NICE guidelines are insufficiently detailed in some areas. Therefore there needs to be a mechanism for the NHS to develop more detailed service specifications.

Recommendation 79: Clinical Reference Groups within NHS England should work with NICE and its other stakeholders to decide when clinical guidelines need updating. NICE should ensure that its surveillance and updating processes take into account emerging evidence, changing clinical practice and the ambitions set out in this report. CRGs

should take responsibility, with support from NICE, to develop clinical guidelines into more detailed service specifications where necessary by the end of 2016. CRGs should take responsibility for developing minimum service specifications where patient volumes are too low to be covered by a NICE clinical guideline, for example for rarer cancers.

NICE should ensure that all research recommendations resulting from guideline reviews are channelled through to NIHR and NCRI for consideration.

8.4 QUALITY ASSESSMENT

Section 8.2 of this strategy sets out how providers and commissioners will be accountable locally to their populations through Cancer Alliances.

The formal regulator of quality in the system nationally is the Care Quality Commission, which monitors, inspects and regulates all health and adult social care services to make sure they meet fundamental standards of quality and safety. Over the past two years the CQC has introduced a radical new approach to inspection of primary medical services, hospitals, community and mental health services and adult social care services. Five key questions are addressed through these inspections: Is the service safe? Is it effective? Is it caring? Is it responsive to patients' needs? Is it well led?

The CQC is currently considering extending the scope of its inspections. It is looking to focus on some common conditions which cut across core services and populations. Taking a condition-based approach would facilitate assessment of care delivered across complex pathways. Cancer would be an excellent exemplar. An opportunity exists to embed some key cancer metrics within the CQC quality assurance framework, building formal accountability where previously there has been a void. This represents a unique opportunity for a joined-up assessment of performance, given that the CQC has reach across all settings in the cancer pathway. For example, in primary care this could include:

- Approaches to monitoring the health of the population served e.g. advice on smoking, obesity, alcohol consumption
- The use of recognised algorithms to assess risk in patients with symptoms that could potentially be due to cancer
- Referral rates for diagnostic tests
- Safety netting processes
- Significant event analyses
- Fast tracking of patients with possible recurrence of cancer
- Use of end of life care registers and electronic palliative care coordinating systems

In secondary/tertiary care this could include:

- Access to and quality and accuracy of diagnostic services and timelines of reporting
- Activity levels and outcomes for cancer surgery, chemotherapy and radiotherapy
- Multi-disciplinary team working and compliance with NICE guidance
- Patient experience through the Cancer Patient Experience Survey (CPES)
- Acute oncology service provision, for patients presenting with complications of cancer and its treatment
- Access to clinical nurse specialists or keyworkers
- Integration between providers of cancer services (primary, secondary and tertiary)
- End of life care provision
- Provision of data to national clinical audits and to the cancer outcomes services dataset (COSD), diagnostic imaging dataset (DID), and systemic anticancer therapy dataset (SACT)

Recommendation 80: CQC should develop an approach to assessing the quality, safety and efficiency of cancer services in primary care, in hospitals and in community health services.

The Quality Surveillance Programme (previously known as National Peer Review) is a quality assurance programme for reviewing clinical teams and services to determine their compliance against national measures. It encompasses a whole systems approach to quality and safety in relation to patient experience and clinical outcomes. Over the years, the peer review programme has been credited with highlighting significant opportunities for improvement, which have subsequently been implemented, such as multi-

disciplinary team-working, enhanced recovery programmes and the increasing provision of nurse-led services. The latest peer review report indicates that compliance with peer review measures is high overall. More than half of multi-disciplinary teams have greater than 90% compliance. But 2% of clinical teams still have lower than 50% compliance with peer review metrics[134]. Recently, the peer review process has been streamlined to make it less bureaucratic and burdensome on providers. There is now a need to reform the process further to enable it to support service improvements within the new commissioning structures and to recognise the role of CQC.

Recommendation 81: NHS England, CQC and Monitor should assess the opportunity to align quality surveillance processes across the cancer pathway by the end of 2015.

The delivery of cancer services spans a number of complex areas, and for certain cancer types it remains vital that we evaluate delivery in detail. The role of national clinical audit in driving improvement in the service cannot be overestimated. The clear focus on outcomes that the annual lung cancer audit has highlighted has undoubtedly led to improvements in how and when we deliver curative treatment across the country. Audits for other cancer types may also be beneficial, but may not be required annually. Similarly, a focus on other parts of the pathway which we know to be critical in terms of impact on outcomes will enable the system to learn where the opportunities for change exist. For example, Cancer Research UK and RCGP are working with PHE, NHS England and others to establish an annual national audit of cancer diagnosis. It is possible that taking part in these audits and associated Significant Event Analyses could be part of GP appraisal and revalidation.

Recommendation 82: NHS England should commission a rolling programme of national clinical audits for critical cancer services, e.g. annually for lung cancer, and oversee an annual audit of cancer diagnosis.

Finally, health professionals have a vital role in driving continuous system improvement. They need to be supported in, and take ownership of, measuring their own performance and adhering to processes which are known to promote good outcomes.

8.5 WORKFORCE

The sustainability of the NHS is critically dependent on having sufficient capacity and the optimal skills mix within its workforce. The growth in the number of cancer cases of 2% per year, coupled with the broader range of services required as more patients survive, is leading to rapid growth in demand. Changes to working practices are adding to these pressures, particularly with the move to seven-day working. Health Education England has recently set out a workforce strategy which addresses a number of areas of importance[135]. It highlights the need for the whole of the system to be identifying workforce needs, from providers and commissioners through to patient groups and Royal Colleges. We have already seen a significant focus on the primary care workforce.

8.5.1 Strategic approach to the cancer workforce

To date, the NHS has not developed workforce planning proposals across entire care pathways and in different settings such as in the community. It is therefore missing opportunities to identify how changes to skills mix can be used to optimise delivery and maximise supply and retention of staff. In addition, there is a strong case for setting out a more strategic approach to workforce for the future in light of the pace of innovation in cancer care and the increasing demands of an ageing population. A shared vision and strategy for the cancer workforce would enable us to find sustainable ways to fill current gaps and adopt a skill-mix approach to care. This would need to include:

- Addressing immediate workforce gaps.
- Breaking down barriers in how care is provided to improve coordination of care.
- Ensuring the workforce has the right skills, training and behaviours, as well as the right support, to confidently deliver high quality and compassionate care.
- Valuing informal carers and volunteers as part of cancer care teams, and ensuring

they have the skills, knowledge and support to provide care.

Recommendation 83: Health Education England should work with NHS England, charities and others to develop a vision for the future shape and skills mix of the workforce required to deliver a modern, holistic patient-centred cancer service. This review should consider training needs for both new and existing NHS staff and should report by the end of 2016.

8.5.2 Deficits in diagnostic services

We currently have a serious shortage of radiologists in England. The existing workforce has so far absorbed increases in demand[xxviii] but as workforce growth has not kept pace, the consequence has been a drop in service quality. This is reflected in the increasing delays in delivering test results to patients. Further increased demand – not least because of the increased levels of investigative testing envisaged in this strategy – will exacerbate the problem.

The UK has around 47 trained radiologists per million population, a figure which has increased only slowly over the past five years[136]. In Germany the comparable figure is 81, in Sweden 108 and in Denmark 121. Approximately half of the workload in radiology services is cancer-related. More than a third of the radiologist workforce is aged 50 or over, and around a quarter will be approaching retirement age in the next five years[137]. Experiments to outsource complex imaging have been unsuccessful so far, largely because treating clinicians need to have regular dialogue with radiologists to determine the best treatment options. Where scans have been outsourced, clinicians have often resorted to repeating scans, which is highly inefficient.

The RCR has estimated that England should be aiming at a minimum of 80 trained radiologists per million population over the next 7 years. Some of this growth can be achieved by increasing training positions by 60 per year over the next five years, from the current 220-230 per year[136]. Health Education England (HEE) has already taken some steps towards increasing training numbers, and will need to do so again in the coming years. However, this will be insufficient to meet demand in the short term (see below).

Endoscopy services are crucial to the delivery of safe and effective bowel screening programmes and the diagnosis of gastrointestinal (GI) cancers. They are currently under-resourced and unable to meet demand[xxix]. For example, colonoscopy rates per head of population in England are among the lowest of all developed countries[138]. Endoscopy units appear to have been managing waiting times to cope with increases in demand. However, this has often meant putting on regular waiting list initiative sessions at weekends and in the evenings. Or it has meant bringing in external staff through agencies to use their facilities during these times. These arrangements come with additional costs which are unsustainable. Furthermore, it is clear that even these measures are insufficient. Deficits are inhibiting the optimal roll-out of bowel screening and preventing increased investigative testing for suspected cancer.

There are some potential quick wins in some areas of the workforce which would optimise the skills mix and fix some gaps rapidly. For example, sonographers currently have to train as radiographers first even though academic bodies and clinical practice no longer consider this necessary. Removing this step would enable us to train more sonographers more quickly. However, this should not be at the expense of quality. Approximately 30% of sonographer workload is for obstetric services, the bulk of the rest is for cancer or suspected cancer[xxx].

Across the country, many posts in diagnostic services remain unfilled, with hospitals giving up advertising after multiple unsuccessful attempts to recruit. Our ambition to see a shift in stage of cancer diagnosis will only happen if we are able to tackle this workforce need.

Recommendation 84: Health Education England should support improvements in the earlier diagnosis of cancer by:

- **Working with the Royal College of Radiologists (RCR) and diagnostic**

[xxviii] Over the last 10 years, the number of MRI scans has increased by 12% p.a. and the number of CT scans by 10% p.a.
[xxix] Research commissioned for the Taskforce, as yet unpublished
[xxx] Research commissioned for the Taskforce, as yet unpublished

experts in NHS England to review, on an annual basis, the number of radiology, diagnostic radiographers and nurse endoscopy training positions required to meet projected needs, and act urgently to address these needs.

- **Work with the RCR to understand better a predicted workforce deficit in breast radiology and develop a plan to address this.**
- **Work with DH and the SCoR to make sonography a separate registration.**
- **Ensure that the quality of training is not compromised in the urgency to increase staff numbers.**

Training more specialists to address workforce deficits takes several years. We therefore need to consider alternative approaches. Across certain disciplines, where there is currently an acute workforce deficit, there is a strong case for having a more coordinated approach to the international recruitment of specialists into England. For example, there is a surplus of well-trained radiologists in the Netherlands and an acute shortage in England. Currently we are overly reliant on individual providers seeking recruits internationally, which means we are not as successful as we could be. It can also mean we don't have a pool of candidates that we can match to where the need is greatest. It is essential that the Royal Colleges become more supportive of the need for international recruitment to fill gaps in areas where demand currently significantly outstrips supply.

Recommendation 85: Health Education England, as part of its careers service responsibility, should develop a programme for international promotion of specialist recruitment opportunities in key areas where shortfalls currently exist and where future demand is expected to grow.

8.5.3 Deficits in treatment and care workforce

Pressures also exist within the treatment workforce. This prevents some patients being seen quickly and receiving the best possible care and support. In some parts of the country, workforce deficits in oncology mean that it is not possible to deliver optimal treatment safely. Success with earlier diagnosis will increase demand for some secondary care services and support services for those living with and beyond cancer. If more patients are seeking treatment with a curative intent and surviving their cancers for longer, and more people are living for longer with treatable but incurable cancer, we will need a workforce of sufficient capacity to be able to respond.

In radiotherapy, guidelines developed in 1985 indicated that treatment should start within two weeks[139]. However, this is still not being achieved 30 years later. In other countries in Europe, many centres routinely commence treatment within 5 days. The limiting factor is access to radiation oncology expertise, therapy radiographers and radiotherapy medical physicists. In medical oncology, demand has been growing by up to 12% p.a. over the last ten years[xxxi]. The increase in demand is driven by the increase in the number of cancer cases, patients having longer duration of treatment as they live longer and treatment options increase, and the advent of acute oncology services. However, more than 30% of medical oncologists are employed wholly or partly by academic institutions, with less than 60% wholly by the NHS. This is the lowest level for any medical specialty except clinical pharmacology and metabolic medicine, both of which are much smaller specialties.

In projecting future workforce needs, there is a disconnect between what the need is from the perspective of providing a high-quality patient-centred service, and what employers are conveying to HEE as *demand*, which is usually deflated to the level employers think will be affordable. This disconnect needs to be addressed, with an immediate focus on medical oncology, radiation/clinical oncology and CNSs. For example, the Association of Cancer Physicians (ACP) has estimated that the consultant medical oncology workforce needs to grow to around 1 per 100,000 population, meaning around 580 FTEs by 2020, compared with 330 now[xxxii]. With the advent of new clinically

[xxxi] Association of Cancer Physicians' strategy - as yet unpublished

[xxxii] The European Society of Medical Oncology has calculated that the UK currently has the highest ratio of population to medical oncologists[140].

effective therapies, the need is likely to grow further to around 1 FTE medical oncologist per 80,000 population, beyond 2020. However, given that in England a large proportion of systemic therapy is delivered by clinical oncologists, a new integrated workforce model needs to be agreed between RCR, ACP and HEE to determine staffing needs for the future. The configuration of clinical and medical oncology in each area needs to be appropriate to the mix of cancer types, academic activity and leadership roles in each centre.

CNS posts have increased for some areas of practice in England between 2007 and 2014. However, the specialist adult cancer nursing workforce in general is not expanding sufficiently to keep pace with the growing number of people with cancer[141]. There is an urgent need for investment in cancer specialist nursing roles, particularly in rarer cancers and certain geographies.

Recommendation 86: Health Education England should support improvements in the treatment of cancer by:

- **Reviewing its modelling processes to reflect better the workforce needs required to deliver a high-quality, patient-centred service, using international benchmarks where necessary.**

- **Once the need has been more clearly delineated, increasing the number of clinical oncology, medical oncology, medical physics, therapy radiography and CNS training positions with immediate effect to address this need.**

In the future, the role of genomic medicine will transform how we deliver healthcare for some in the population. However this will only happen if we are able to equip our workforce appropriately. The 100,000 Genomes project currently underway is already looking at the potential implications for the workforce of genomics. We have recommended in this strategy that the NHS should deliver molecular diagnostic testing to inform prevention, screening and treatment of cancer. For this to benefit all patients, we will need to consider how the workforce needs to be equipped to access clinical scientist expertise, and how we will meet the rising demand in molecular pathology.

Recommendation 87: Health Education England should work with the Royal College of Pathologists and others to determine how best to equip the workforce to meet the future demand for molecular pathology and clinical scientist expertise.

8.5.4 Optimising workforce deployment

There is more we could do to optimise how the workforce is deployed, in addition to increasing staff numbers in those areas where we are facing shortfalls. A number of barriers exist which inhibit the best deployment of workforce across provider boundaries. This ultimately impacts on patient care. We know that in some parts of the country patients are not being offered the treatment that would be best for them because visiting medical oncologists do not have capacity. Similarly, in radiotherapy, it is unrealistic to expect every provider to have the workforce and equipment to support access to every innovative technique. But currently we are not networking effectively to facilitate regional access for patients within a geographic area.

We need to start breaking down some of these barriers between providers. Some of this will be achieved through commissioning across larger populations (see 8.1). However it is also appropriate to consider other models. If one provider were able to manage the treatment budget for an entire population, they would have oversight of how best to deploy scarce resources across providers to serve that population. For example, some providers already enable CNSs and oncologists to work in other hospitals on a part-time basis, while ensuring rotation through the lead provider to maintain service quality. Long term success in this approach relies on taking forward recommendations in the Dalton Review, and the principles set out in the FYFV, with providers coordinating and collaborating more. It will be important to agree upfront, in any such models, which services need to be provided locally, so that not all services are moved to the lead centre, to the detriment of patient convenience.

Recommendation 88: NHS England should pilot all secondary/tertiary cancer treatment services provided through a 'lead provider' in 2-3 new or existing vanguard areas. The lead would manage the entire treatment budget.

In radiology, the RCR has proposed the development of radiology networks as a means of overcoming current workforce deficits[142]. These networks would serve populations of several million rather than a few hundred thousand, as at present. They would involve groupings of 150-200 radiologists, who would be able to provide continuous 24-hour cover across 5-6 hospitals. However, delivering this will require much more effective collaboration across providers, supported through IT and tele-radiology resource to flex capacity. NHS England should encourage and facilitate the development of these radiology networks to make better use of scarce consultant radiology resources across provider boundaries.

8.6 CANCER DATA AND INTELLIGENCE

The commitments in this strategy will rely on high-quality, and in many instances near real-time, cancer intelligence capability. There have been significant improvements over the last five years in the systematic collection of cancer data, with the modernisation of the National Cancer Registration Service (NCRS) and the development of the Cancer Outcomes and Services Dataset (COSD). The completeness and accuracy of England's cancer data is amongst the best in the world. However, the last few years have been very challenging for data analytics and linkage following changes in responsibilities and associated legislation introduced by the Health and Social Care Act 2012. Significant operational bottlenecks have also arisen in key organisations, including the Health and Social Care Information Centre, the Clinical Practice Research Datalink and Public Health England. Information governance processes across different organisations have been complex, opaque to end users and sub-optimal in other ways. The result has been that researchers and analysts have been unable to access data in a timely manner. This has held back progress in using patients' data to address fundamental cancer service questions aimed at improving outcomes.

Recommendation 89: DH should urgently address the current information governance problems around access to NHS patient data experienced by bona fide clinical and research organisations which are compliant with appropriate standards of data security and confidentiality. It should ensure that a policy and legal framework is in place that facilitates the ongoing flow of data from and between HSCIC, MHRA, NIHR, and PHE.

An inability to link data sets and make these available to providers, commissioners and researchers sustains the provision of sub-standard care. There is extensive evidence that cancer patients want their data to be used for research and to improve care. We must harness their support, ensuring cancer patients are placed at the heart of strengthening our cancer data intelligence. We must resolve current challenges and ensure that cancer intelligence capacity is capable of dealing with increased demands. This includes the needs associated with the initiatives set out in this report.

The National Cancer Intelligence Network within PHE plans to refocus on the systems, governance and people required to ensure outstanding commitments are met and built upon. In particular, they will explore more innovative linkage, including to social care, mental health, protected characteristics (such as sexual orientation and ethnicity) and SES to enable better measurement of inequalities. It is planning to continue to develop the range and quality of its outputs to help patients, clinicians, commissioners and provider organisations improve quality and outcomes. The additional resource required should be amply covered in benefits in the quality and outcomes of care that an enhanced intelligence function would support.

Better data collection is needed if we are to understand and implement the best methods for preventing recurrent and secondary cancer. All NHS trusts should now be recording recurrent and secondary breast cancer patients, but uptake has been

slow. There is no requirement for Trusts to record this data for other types of cancer. However, recording this data would improve our understanding of when cancer recurs, to whom, after which treatment pathway, and how it can be best detected. This information could be crucial in improving secondary prevention.

Recommendation 90: Public Health England, working closely with partners in a newly constituted PHE Cancer Board, should improve the provision of cancer data and intelligence via the National Cancer Intelligence Network and the National Cancer Registration Service:

- **Greater focus should be achieved by ensuring adequate resources are applied to collect comprehensive cancer data, link it across the whole cancer pathway and analyse it through a centralised data system.**
- **PHE should work with charities and researchers to clear the existing backlog of data requests from commissioners and researchers by the end of 2015. Thereafter, PHE, through NCIN and NCRS, should work to establish further linkages of datasets, including RTDS, CPRD, SACT, and DID to help drive further service improvement.**
- **Public Health England and NHS England should establish robust surveillance systems and, if possible, mandate the collection of data on recurrent and secondary cancer occurrences for all cancers and make this available for analysis and research.**

8.7 RESPONSIBILITY FOR IMPLEMENTING THE STRATEGY

Ensuring delivery of this strategy and continual development of cancer policy will require an oversight team that can coordinate activities across the seven arm's length bodiess (ALBs). This team could either be hosted in one of the seven or commissioned externally. This team would also ensure learning is shared across the country through attendance at Cancer Alliance meetings. This National Cancer Team (NCT) should collate, analyse and interpret learning from local initiatives and evidence regarding variation, and share this intelligence with Alliances to drive improvement. Where possible, evidence studied will include inequalities relating to cancer types, socio-economic background, age, and other factors. The NCT should also oversee the development, resourcing and support of cancer CRGs, commission reviews of specific cancer services from CQC where appropriate, and commission the rolling programme of national audits.

Recommendation 91: The seven ALBs should establish a properly resourced National Cancer Team (NCT) to oversee implementation of this strategy.

CRGs will need to be properly resourced to deliver the functions set out in this strategy. CRGs have overlapping membership with NCRI Clinical Studies Groups and NCIN Site Specific Clinical Reference Groups and the various groups should be encouraged to work together under a single operating model, with better clarity of respective roles. It may also be useful to have observers from Scotland, Wales and/or N Ireland on CRGs to encourage as much consistency of approach as possible across the four nations.

Recommendation 92: The NCT should ensure that CRGs are properly resourced to deliver the functions set out in this strategy.

As in previous years, we expect that individual strands of the strategy will be overseen jointly with key charities, for example:

- The National Awareness and Early Diagnosis Initiative will continue, jointly chaired with Cancer Research UK.
- The National Living With and Beyond Cancer Programme will continue, jointly chaired with Macmillan Cancer Support.
- The National Cancer Intelligence Network, will continue to deliver critical data and intelligence and will be jointly chaired between NHS England and PHE, with the continued involvement of Cancer Research UK, Macmillan Cancer Support, the National Cancer Research Institute and other relevant charities as appropriate.

8.8 NATIONAL ACCOUNTABILITY

One of the criticisms made following the last NHS cancer strategy is that fragmentation in the system has led to insufficient accountability. We recommend addressing this by creating a National Cancer Advisory Board, independently chaired, to oversee and "hold a mirror" up to the NHS on aspects of implementation of the national strategy. This body would include representation from national charities, patients and Royal Colleges and would prepare an annual report for the CEOs of the seven ALBs and the Secretary of State for Health.

Recommendation 93: NHS England should sponsor a National Cancer Advisory Board, independently chaired, to oversee and advise on implementation of the national strategy. This body should prepare an annual report for the CEOs of the seven ALBs and the Secretary of State for Health.

In addition to national implementation oversight, it will be important to deal with local systems that are consistently failing to deliver adequately to agreed national standards.

Recommendation 94: The National Cancer Team should have the responsibility of directly informing the CEO of NHS England of CCGs or providers which are consistently failing to deliver against national metrics.

8.9 VALUE FOR MONEY

The National Audit Office has recently criticised the NHS for having an insufficiently informed understanding of the costs and value for money of delivering different aspects of cancer services[16]. This is not a problem that is specific to cancer services. However, this strategy provides a catalyst to address this need, which can then be extended to other service areas. The NCT should commission improved intelligence on the costs and value for money of different aspects of cancer services, to help inform future cancer strategies and to address criticisms made by the National Audit Office.

Recommendation 95: NHS England and Public Health England should work with Monitor and other bodies to consider how to develop better health economic evaluation of new service models and interventions.

8.10 BEYOND 2020

Our knowledge and understanding of cancer continues to grow, as does our ability to design services around how best to tackle cancer. This report sets out what needs to be put in place over the next five years based on our knowledge now. But this shouldn't constrain us from constantly evolving our services as we understand more. Furthermore, the improvements that arise from revising strategic direction in cancer services on a regular basis have been clearly demonstrated. The NHS should constantly monitor the evidence base and horizon scan as it implements the strategy, with a view to setting out a new set of initiatives to take us beyond 2020.

9. HOW MUCH WILL IT COST?

Chapter Summary

- The cost of cancer in the NHS is likely to grow rapidly due to increasing incidence, healthcare inflation and new technology. This is without taking any of the actions outlined in this report. Some of these cost increases have already been taken into consideration in the Five Year Forward View baseline assumptions
- A number of initiatives in this strategy will require additional investment, including one-off capital costs
- Investment in these initiatives will unlock savings that will contribute to the £22bn efficiency savings the NHS is aiming to realise
- Further work is required to finalise the estimated costs and savings

9.1 COSTS DRIVEN BY GROWTH IN DEMAND, INFLATION AND NEW TECHNOLOGY

In the absence of this strategy, cancer costs in the NHS would be likely to grow rapidly, given the 2% per annum growth in the number of people diagnosed and general growth in health care costs. The National Audit Office estimated NHS costs related to cancer of £6.7bn in 2012/13, while acknowledging that this does not capture all costs, such as some of those incurred in primary care. In addition to this, approximately £0.8 - 1bn is spent in the private sector and a further £0.6 - 0.8bn in the voluntary sector.

The FYFV forecasts were based on a Technical Annex published in December 2013, which included assumptions indicating that budget lines related to cancer are likely to grow by around 9% per annum over the next five years, in the absence of any efficiency savings:

1.4% p.a.	Acute/specialised cost growth due to demographics (age and population growth)
3.5% p.a.	Specialised cost growth due to non-demographic factors (technological advances)
3.9% p.a.	Specialised health cost inflation (includes pay, drugs, other factors).

This would indicate that NHS cancer costs would grow to around £13bn by 2020/21.

9.2 SPECIFIC INITIATIVES IN THE STRATEGY – COSTS INCLUDED IN BASELINE

Much of the projected growth in the cancer budget will be consumed through staffing levels. The costs of training and employing additional staff to cope with increases in cancer demand is assumed to be included within baseline assumptions. A number of the specific recommendations in the strategy have costs that are also considered - wholly or partly - to be included in the FYFV baseline assumptions, including (in 2015/16 prices):

Be Clear on Cancer[xxxiii]	£5.5m p.a.
Recovery package/ Stratified Follow-up Pathways [xxxiv]	£8.5m p.a.
Molecular diagnostics for solid cancers	£8.0m p.a.
Excess treatment costs for radiotherapy trials	£1.2m p.a.
Sub-Total	£23.2m p.a.

[xxxiii] These campaigns have been funded since 2009 and therefore are considered to be in the baseline. However, this money is not ring-fenced and as such we recommend the NCT and DH plan for campaigns each year over the course of the strategy.
[xxxiv] Initial roll-out included in 2015/16 NHS England Business Plan

The strategy calls for a substantial increase in investigative testing, largely to drive earlier cancer diagnosis. It is unclear how much of the additional demand is already assumed within the FYFV baseline projections. For example, we estimate that the volume of some of these tests needs to grow by 70-80% over the next five years, compared with an estimated 10% growth in the number of cases. Over the last ten years, the volume of CT and MRI scans has been growing by 10% and 12% per annum respectively, or 60-75% over five years.

The activity modelling which supported the FYFV included 7% growth in overall diagnostic activity year on year to 2020/21. Around half of this will be for cancer. The ambition we have set out in this strategy envisages a step change in delivery of diagnostics by the NHS including meeting the NICE guidance of a threshold of 3%. At this stage it is difficult to model the impact of the step change given the growth already included in the baseline and the differing starting position of CCG commissioners in terms of the scope of services they currently provide. We estimate the costs of incremental testing in excess of the FYFV baseline to be within a range of £75m to £300m[xxxv] per annum by year 5.

In addition, to support local health economies to transition to the new threshold we are proposing a national diagnostic capacity fund of £25m per annum.

Delivering appropriate end of life care has already been accepted as a priority for the NHS. As such, the costs are not considered to be incremental as a result of this strategy.

Establishing Cancer Alliances and properly resourcing Clinical Reference Groups, whilst not significant in cost terms, are pivotal to delivering the strategy. Part of the resource required can be reallocated from existing activity, such as Strategic Clinical Networks and AHSNs.

9.3 SPECIFIC INITIATIVES IN THE STRATEGY – INCREMENTAL ANNUAL COSTS

The strategy includes a number of recommendations that would add incremental costs to those included in the FYFV baseline. These are estimated as follows (in £m 2015/16 prices[xxxvi]):

Recommendation	2016/17	2017/18	2018/19	2019/20	2020/21
Prevention and screening:					
- **HPV Testing**	2.0	2.5	1.0	1.0	1.0
- **FIT**	1.0	5.0	4.5	4.5	4.5
Early diagnosis:					
- **Additional diagnostic capacity**	15.0 – 60.0	31.0 – 125.0	46.0 – 190.0	62.0 – 250.0	75.0 – 300.0
- **Diagnostic capacity (national fund)**[xxxvii]	25.0	25.0	25.0	25.0	25.0
Molecular diagnostics (incremental)	2.5	3.5	5.5	5.5	5.5
Living with and beyond cancer:					
- **Recovery package (incremental)**	27.0	29.5	30.0	31.0	31.5
- **Stratified pathways (incremental)**	12.0	12.0	7.0	7.0	7.0
Commissioning and data sets:					
- **DID/cancer wait times**	0.5	0.5	0.5	0.5	0.5
- **New metrics/additional NCIN cost**	1.5	1.5	1.5	1.5	1.5
ETCs for radiotherapy studies[xxxviii]	4.3	4.3	4.3	4.3	4.3
Pilot activity (various)	4.5	4.5	4.5	4.5	4.5
Cancer Alliances/CRGs (incremental)	3.0	3.0	3.0	3.0	3.0
Sub-Total	98 - 143	122 - 216	133 - 277	150 - 338	163 - 388

[xxxv]The lower end of this range is based upon all CCGs moving to the 50th percentile of current diagnostic activity, resulting in an activity growth rate of 8.4% per annum with the top end of the range based upon all CCGs moving to the 10th percentile of current diagnostic activity, resulting in an activity growth rate of 10.9% per annum.

[xxxvi]Only for costs in excess of £0.5m p.a.

[xxxvii]Central fund used flexibly to unlock local capacity increases

[xxxviii]Incremental

It is possible that all pilot activity set out in this strategy could be funded from the Transformation Fund. However, we have included a separate budget for this activity in case the Transformation Fund is not available. Roll-out costs will only be incurred if these initiatives are subsequently implemented. This will take some time to establish and has not been estimated here.

9.4 SPECIFIC INITIATIVES IN THE STRATEGY – INCREMENTAL CAPITAL COSTS

The strategy recommends that all linacs are replaced as they reach 10-year life and are upgraded as they reach 5-year life. Over the next five years, this implies the replacement of 126 linacs and 58 upgrades. The capital costs of these are estimated at £252m and £23m respectively over the five years, or £222m and £20.5m, inclusive of 12% procurement savings. In practice, it should be possible to achieve at least 30% procurement savings with this scale of investment and a limited number of suppliers. This equates to an additional £50m of savings over the five years, with a resulting cost of £192.5m.

The strategy also recommends investment in dedicated MR and PET imaging facilities for radiotherapy planning in major treatment centres. The costs of these facilities are estimated at £20m over five years, inclusive of estate costs.

9.5 COST SAVINGS – CONTRIBUTION TO THE FUNDING AND EFFICIENCY GAP

A number of the initiatives in this strategy will deliver savings which will contribute to the £22bn efficiency savings that the NHS is aiming to realise by 2020. These savings will likely be delivered a year or two after the initial investments have been made, with some landing several years later. The major opportunities are estimated as follows:

- Introduction of HPV testing for cervical cancer screening. This test will enable a reduced screening interval, the saving from which is estimated at £35m p.a. by 2020/21;
- Earlier diagnosis of cancer. If all areas of the country are able to achieve by 2020 a stage distribution equivalent to the best CCG in England, the treatment savings across four types[xxxix] of cancer have been estimated by Cancer Research UK at £44m p.a., since the cost of treating an early stage cancer is much lower than treating a later stage cancer. Extrapolating to all types of cancer would enable treatment savings of £210m p.a. to be realised;
- Direct GP access to tests. We have estimated that it should be possible to save around 700,000 consultant appointments per year[xl]. Even if all these appointments were replaced by GP appointments, the saving would be approximately £85 per appointment, i.e. a saving of £60m p.a. However, the savings could reach £256m p.a.[xli] or even higher[xlii];
- Recovery package and stratified pathways. Early pilots have indicated that these approaches to living with and beyond cancer should be, at worst, cost neutral. Therefore, it should be possible to achieve downstream savings of around £47m p.a.
- Procurement savings from linacs. Without a central programme, linacs would still need to be replaced. Assuming centralised procurement savings of 30% are achieved, this amounts to up to £82.5m over five years, or around £16.5m p.a;
- Obviating growth in linac capacity. The upgrading of linacs to enable higher throughput and more sophisticated provision with up to date techniques means that we do not expect to need to increase the installed base of linacs as the number of patients diagnosed with cancer increases. Without this, we would expect to need an additional 25-30 linacs

[xxxix] Colon, rectal, ovary and non-small cell lung cancers. In fact, better stage distribution for lung cancers would incur an increase in treatment costs of approximately £6mp.a. Savings in the other three types of cancer are estimated at £50m p.a.

[xl] Assumes all CCGs match the 80th percentile for GP direct access, with one specialist appointment being replaced by a GP appointment

[xli] Assumes all CCGs match the 80th percentile for GP direct access, with two specialist appointments being replaced by a single GP appointment, and assuming growth in the number of tests of 50% by 2020

[xlii] The highest levels of GP direct access for MRI and CT are 29% and 30% respectively. There is therefore the potential to go much higher. It is up to 100% in other countries (see section 5.2.2)

over the next five years, to cope with the estimated 10% growth in demand. At £2m per linac, this amounts to a saving of £50-60m over the five years, or around £10-12m p.a.

In total, the above savings amount to between £380m and £575m p.a. which would start to accrue from 2018 onwards. Furthermore, this excludes the savings that would accrue from:

- enhanced primary and secondary prevention;
- the use of molecular diagnostics to obviate treatment that will provide no benefit to patients;
- appointments or scans having to be re-scheduled because clinicians are unable to access test results;
- earlier detection of other conditions through increased use of investigative tests;
- better management of other conditions through more holistic approaches to living with and beyond cancer.

These savings opportunities have not been quantified in this report but are expected to be substantial in all five areas. Historically, it has been difficult to "extract" identified savings in the NHS, given implications for staffing and physical infrastructure. In the case of cancer, these savings should be easier to deliver, as they will largely represent a reduction in the rate of growth of spend, through using existing resources more efficiently to cope with increased demand.

Finally, as noted in section 8.9, we have found it difficult to identify all of the costs and potential savings associated with the initiatives set out in this report. In particular, it has been difficult to assess "whole-system" implications, such as those which would result from the recommendations around earlier diagnosis.

Recommendation 96: NHS England should work with Monitor to develop a health economics approach to assess the costs and benefits associated with programmes of work in cancer, e.g. early diagnosis, in order to better quantify the associated costs and savings.

ANNEX A: METHODOLOGY AND ACKNOWLEDGEMENTS

METHODOLOGY

1. TASKFORCE

The Independent Cancer taskforce was established by NHS England on behalf of the Care Quality Commission, Health Education England, Monitor, Public Health England and the Trust Development Authority in January 2015 to develop a five-year strategy for cancer services. Dr Harpal Kumar, Chief Executive of Cancer Research UK, was appointed as independent chair, with membership representing a cross section of the cancer and health community.

Full membership of the Independent Cancer Taskforce:

Harpal Kumar – Chair
Shafi Ahmed – Royal College of Surgeons
Jane Allberry – Department of Health
Maureen Baker – Royal College of GPs
Juliet Bouverie – Macmillan Cancer Support
Adrian Crellin – Radiotherapy Clinical Reference Group
Sean Duffy – NHS England
Kevin Hardy – St Helens and Knowsley Teaching Hospitals NHS Trust
Anne-Marie Houlder - NHS Stafford and Surrounds CCG
Liz Hughes – Health Education England
John Newton – Public Health England
Clara Mackay – Cancer 52
Kathy McLean – NHS Trust Development Authority
Catherine Oakley - UK Oncology Nursing Society
Cally Palmer – Royal Marsden
Martin Reeves – Coventry City Council
Mike Richards – Care Quality Commission
Richard Stephens – Patient Representative
Sarah Woolnough/ Sara Hiom – Cancer Research UK

The taskforce met monthly from January to June to advise on the development of the strategy. Individual members provided expertise across a number of areas, attended relevant stakeholder events and advised on drafting. In March 2015 the Taskforce published a Statement of Intent[xliii] which assessed the opportunity for improved cancer care. The taskforce was supported by a secretariat with staff from Cancer Research UK, Macmillan Cancer Support, NHS England, Public Health England and the Department of Health.

2. STAKEHOLDER ENGAGEMENT

Large numbers of organisations and individuals have been involved in the creation of this strategy. We would like to thank all those who have contributed their time and input.

[xliii] http://www.cancerresearchuk.org/about-us/cancer-taskforce

2.1 WRITTEN SUBMISSIONS

The taskforce held a call for evidence over six weeks in January and February 2015 and this was promoted by members of the secretariat to the wider cancer and health community. 226 responses were received. A full analysis has been published alongside this strategy, including details of who submitted evidence.

In addition, the taskforce secretariat has managed a taskforce email account answering queries from, and coordinating correspondence with, stakeholders and the public.

2.2 WORKSHOPS AND MEETINGS

Stakeholder workshops and meetings were hosted by the taskforce. Some of these were held with specific stakeholder groups, whereas others were held on a subject area with a cross section of interested stakeholders. A taskforce or secretariat member attended each of these events and a record of the discussion was taken. A full list of stakeholder events is given in the box below.

Workshops were held with the following stakeholder groups:

- Charities
- Industry
- Clinical Oncologists
- Consumer Liaison Group
- Pathologists
- Patients (Newcastle, Birmingham and London)
- Commissioners
- Primary Care
- Medical Oncologists
- Surgeons
- Nurses and AHPs
- Radiologists
- Early career clinicians and nurses

Meetings were held on the following topic areas:

- Older People
- Children and Young People
- Prevention
- Data
- Screening
- Research
- End of Life
- Living with and beyond cancer
- Information
- Digital
- Patient Experience
- Levers and incentives
- Local organisation and accountability
- Early Diagnosis

The taskforce chair, taskforce members and secretariat staff also held meetings with individual stakeholders and organisations. An Equality Impact Assessment has been conducted to assess the recommendations, which has been published alongside this report.

ACKNOWLEDGEMENTS

The Independent Cancer Taskforce would like to thank the following individuals for their support:

Sara Bainbridge, Affonso Bennett-Williams, Stephen Boyle, Joanna Clarke, Alice Cotelli, Tim Elliott, Matt Fagg, Danielle De Feo, Sophie Goodchild, Liz Gould, Emma Greenwood, Fiona Howie, Dan Hughes-Morgan, Lucy Ironmonger, Richard Kelly, Theresa Lawler, Amy Lee, Sean McPhail, Jennifer Mitchell, Nick Ormiston-Smith, Gillian Rosenberg, Nalyni Shanmugathasan, James Shield, Alan Slater, Susan Speece, Laura Thomas, Julie Van der Woude, Rachel White.

We would also like to thank all those who contributed their time and expertise into the development of the strategy and all those who attended meetings and submitted written evidence.

ANNEX B: GLOSSARY AND ABBREVIATIONS

Glossary

Acute Care	For a disease or illness with rapid onset, severe symptoms and brief duration. Also called secondary care.
Adjuvant therapy	A term used to describe additional treatments, such as chemotherapy or radiotherapy, given after cancer surgery
Advance Care Planning	A structured discussion with patients and their families or carers about their wishes and thoughts for their future.
Age standardised	Age-standardised rates cover all ages and are standardised to the European Standard Population, expressed per million people in a population. This allows comparisons between populations with different age structures, including between males and females, or over time.
Be Clear on Cancer	A Public Health England campaign aimed at raising awareness of the signs and symptoms of cancer, delivered in partnership with NHS England, the Department of Health and Cancer Research UK.
Cancer Alliances	Recommended organisational structure bringing together key partners at a sub-regional level, including commissioners, providers and patients.
Chemopreventative agents	The use of drugs, chemicals, vitamins or other substances in the diet to prevent or decrease the incidence of cancer.
Chemotherapy	The use of drugs, singly or more usually in multiple combinations, to treat or cure cancer.
Choice Review	Independent review into choice in end of life care commissioned by the Government and published in February 2015.
Commissioning	The process of assessing the needs of a local population and putting in place services to meet those needs.
Co design	Patients and carers working in partnership with staff to improve services.
Dalton Review	An independent review published in December 2014 and commissioned by the Health Secretary to explore options for providers of NHS care to reduce variations in clinical standards, financial performance and patient safety. The review aims to encourage boards to explore new organisational models.
Enhanced Recovery Programme	A quality and service tool looking to improve outcomes and speed up a patient's recovery following surgery.

Every contact counts	A behaviour change programme which encourages professionals to use every contact with a member of the public to have a conversation to improve health.
Excess treatment costs	The difference between the cost of a normal treatment or intervention and that of the cost of the new or different intervention or treatment that will be tested via research.
Five Year Forward View	Vision for the future of the NHS; published in October 2014 and developed by the partner organisations that deliver and oversee health and care services including NHS England, Public Health England, Monitor, Health Education England, the Care Quality Commission and the NHS Trust Development Authority.
Genomic medicine	A way to customise medical care to an individual's unique genetic makeup (also known as personalised medicine).
Gold Standards Framework	A systematic, evidence based approach to optimising care for all patients approaching the end of life, delivered by generalist care providers.
HeadSmart Programme	A project that aims to enhance the awareness of symptoms of brain tumours in children and young people.
Holistic Needs Assessment	A structured discussion between a patient and their healthcare professional about their physical, emotional and social needs.
Metastatic cancer	Cancer that has spread from the place where it first started to another part of the body (see also *Secondary cancer*)
Molecular diagnostics	Tests and methods used to identify a disease or the likelihood of developing a specific disease by analysing an individual's genomic sequence, tumour mutations or other molecular biomarkers.
Mortality rate	The number of people per unit of population who have died from a particular type of cancer in a year. These figures should be looked at alongside incidence figures and other statistics.
National Cancer Team	Recommended oversight team that can coordinate activities across the seven ALBs.
New models of care	A programme to assess new methods of health and social care delivery set out in the Five Year Forward View.
Pathways of care	Anticipated care placed in an appropriate time frame, written and agreed by a multidisciplinary team.
Patient centred care	Providing care that is respectful of and responsive to individual patient

	preferences, needs, and values, and ensuring that patient values guide all clinical decisions.
Quality Surveillance Programme	(formerly known as National Cancer Peer Review (NCPR)) A quality assurance programme for reviewing clinical teams and services to determine their compliance against national measures.
Safety netting	A diagnostic strategy or consultation technique to ensure timely re-appraisal of a patient's condition.
Screening	Conducting examinations or tests to detect diseases before symptoms are present. Screening allows for detection of diseases in their early, most treatable stages.
Secondary cancer	A cancer which has spread from the original (or primary) cancer to another part of the body (see also *metastatic cancer)*.
Service specification	A document that contains the commissioner's description of what they want from a service. It can be used by the provider to structure their service and by the commissioner to hold the provider to account.
Stratification	The grouping of patients according to specified criteria such as age, risk, or molecular profile.
Survival rate	The percentage of patients alive a defined period of years after they were diagnosed.
Tariff	The calculated price for a unit of healthcare activity paid to providers by commissioners.
Taylor Review	The Accelerated Access Review, chaired by Sir Hugh Taylor, set up to look at faster adoption of innovative drugs, devices, digital health and diagnostics for NHS patients.
Test and learn	The testing of ideas in a small number of locations or with small number of patients to assess impact.
Tomosynthesis	An imaging technique in which multiple X-rays create a three dimensional image of an object.
Vanguard	Sites selected by NHS England to test the new models of care.

Abbreviations Used

5FU	Fluorouracil
ACE	Accelerate, Coordinate and Evaluate

ACP	Association of Cancer Physicians
AHP	Allied Health Professional
AHSN	Academic Health Science Network
ALBs	Arm's Length Bodies
BRCA	Genes which may have mutations linked to an increased risk of breast cancer
BME	Black and Minority Ethnic
CCG	Clinical Commissioning Group
CEO	Chief Executive Officer
CNS	Clinical Nurse Specialist
COSD	Cancer Outcomes and Services Dataset
CPES	Cancer Patient Experience Survey
CPRD	Clinical Practice Research Datalink
CRG	Clinical Reference Group
CQC	Care Quality Commission
CT	Computed tomography
CTYA	Children, teenagers and young adults
CVD	Cardiovascular disease
DCIS	Ductal carcinoma in situ
DCPC	Depression care for people with cancer
DGH	District General Hospital
DH	Department of Health
DID	Diagnostic Imaging Dataset
ER	Estrogen Receptor
ETCs	Excess Treatment Costs
FIT	Faecal Immunochemical Test
FYFV	Five Year Forward View
FTE	Full time equivalent
gFOBt	Guaiac Faecal Occult Blood test

GI	Gastrointestinal
GMC	General Medical Council
HER-2	Human epidermal growth factor
HEE	Health Education England
HPV	Human papilloma virus
HNPCC	Hereditary nonpolyposis colorectal cancer
HSCIC	Health and Social Care Information Centre
HSE	Healthy and Safety Executive
HWBs	Health and Wellbeing Boards
IMRT	Intensity modulated radiation therapy
ITU	Intensive therapy unit
Linac	Linear accelerator
MDC	Multidisciplinary diagnostic centre
MDT	Multidisciplinary team
MHRA	Medicines and Healthcare Regulatory Agency
MR	Magnetic resonance
MRI	Magnetic resonance imaging
NAEDI	National Awareness and Early Diagnosis Initiative
NAO	National Audit Office
NCAT	National Cancer Action Team
NCIN	National Cancer Intelligence Network
NCRI	National Cancer Research Institute
NCRN	National Cancer Research Network
NCRS	National Cancer Registration Service
NCSI	National Cancer Survivorship Initiative
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research

NO Ultrasound	Non-obstetric ultrasound
NSC	UK National Screening Committee
Pap	Papanicolaou
PBT	Proton beam therapy
PET	Positron emission tomography
PHE	Public Health England
PROMs	Patient Reported Outcome Measures
PSA	Prostate specific antigen
QALY	Quality-adjusted life year
RCGP	Royal College of General Practitioners
RCR	Royal College of Radiologists
RTDS	Radiotherapy dataset
QA	Quality assurance
QIPP	Quality, Innovation, Productivity and Prevention
SACT	Systematic Anti-Therapy Dataset
SABR	Stereotactic ablative body radiotherapy
SCoR	The Society and College of Radiographers
SES	Socioeconomic Status
SRS	Stereotactic radiosurgery
SRT	Stereotactic radiotherapy
TYA	Teenagers and young adults
UV	Ultraviolet
VOICES-SF	National Survey of Bereaved People

ANNEX C: REFERENCES

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