

Statement of Intent: Cancer Strategy for England: 2015 - 2020

In January 2015 NHS England, on behalf of the six Arms Length Bodies (ALBs)¹, announced the establishment of an independent taskforce to develop a five-year strategy for cancer services. The taskforce is charged with delivering the vision set out in the NHS Five Year Forward View, working across the entire health system. It will consider prevention, first contact with services, diagnosis, treatment, support for those living with and beyond cancer, end-of-life care, the research environment, as well as how all these services will need to develop and innovate in the future.

We set out here the opportunity to reduce the burden of cancer overall and to improve care for cancer patients; the full five-year strategy will follow in summer 2015. This will be informed by responses to the Call for Evidence, the outputs from around 30 workshops, discussions within the taskforce itself, and wider engagement with patients and the broader health community.

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 we know that our mortality rates are higher than they could be and that there is unacceptable variability in access to and experience of care across geographies, segments of the population and cancer types. We also know that, even with major improvements in prevention, the number of people diagnosed with cancer each year will continue to grow rapidly due to the ageing population. This will place significant additional demand on health and social care services.

Cancer is distinctive because our understanding of its causes and the technologies available to us are advancing at an astonishing rate. Our increasing knowledge of where opportunities exist for improvement, and our ability to use resources differently and in a more targeted way, mean that there is scope to deliver a step-change in outcomes, both in survival and in quality of life, in the years ahead. Realising this potential will require a broad set of approaches, including more integrated pathways of care and increased investment. Many of these approaches would deliver benefits not just for cancer patients, but for patients with a range of other diseases and illnesses.

If, on the other hand, we continue with current approaches to funding and delivery of cancer services, we will be unable to meet demand, NHS resources will be spent inefficiently, and patients will not receive the standard of care that they rightly deserve.

¹ Care Quality Commission, Health Education England, Monitor, NHS England (NHS E), Public Health England (PHE), Trust Development Authority



1. The Landscape for Cancer in England in 2015

1.1 The challenges the new strategy needs to address

i) Cancer incidence

More than half of us in England will be diagnosed with cancer in our lifetimes². There are around 280,000 new diagnoses every year, a number which has been growing by around 2% per annum, i.e. around 5,000 - 6,000 additional new cases each year. On current trends, we can therefore expect to see a further 25,000 to 30,000 new diagnoses each year by 2020, rising to 80,000 additional cases each year by 2030. These figures emphasise the need to plan now for the increased demand we can expect to see, if outcomes are to be maintained or improved. The continuing rise in cases is in part due to the ageing and growth of the population, a result of the overall success of the healthcare system in tackling premature mortality over the last 50 years as people are less likely to die from other conditions, such as cardiovascular disease. But it is also because our changing lifestyles are increasing our individual risk; prevention efforts have, as yet, been unable to stop or reverse this trend at an overall level.

It is estimated that more than 40% of cancer cases each year are caused by aspects of our lifestyles that we have the potential to change. The opportunity to slow down the growth in the number of cases of cancer is therefore predominantly dependent on addressing these lifestyle risk factors. Smoking remains by far the most significant, responsible for more than a quarter of all cancer deaths, despite the reductions in smoking rates we have seen in recent years. Obesity and overweight, poor diet, excessive alcohol consumption and UV exposure are also well documented as risk factors. There are huge variations in the prevalence of these risk factors, often driven by socio-economic, cultural or other differences. For example, people with mental health problems have much higher smoking rates – and reduced life expectancy as a result.

In addition to the new cases diagnosed each year, there are an estimated 2.5 million people in the UK in 2015 who have had a cancer diagnosis, an increase of almost half a million in the previous five years. It is projected that this will rise to 3.4 million by 2030. Many of these individuals have ongoing long-term support or health needs related to their cancer experience.

Cancer is an umbrella term used to describe a vast range of different diseases. There are many hundreds of different types of cancer, with different causality, symptomatic presentation, treatment needs and prognoses. Currently, around half of cancers diagnosed are of the four most common types – lung, prostate, breast and colorectal – and the other half are of types that are rare or less common.

² Based on projections for people born after 1960



ii) Survival and Mortality Outcomes

Cancer survival in England has reached its highest level ever. A combination of sustained progress through cancer research and concerted efforts to address the configuration and quality of NHS services since 2000 have resulted in overall survival one year from diagnosis of 70% (up from 60% in 2000) and median survival across all types of cancer of ten years. Age-standardised mortality rates have steadily declined, having fallen by 11% since 2000. Over the ten-year period to 2013, mortality rates in under-75s fell even faster, by 15%.

Whilst we have made great progress in improving survival for some types of cancer, we have made much less progress in others. In some types of cancer, notably melanoma, breast, testicular and prostate cancers, survival has improved significantly, whereas in lung, pancreas and oesophageal cancer and most brain tumours, survival remains stubbornly low. Research efforts to address these needs must be maintained, both in the UK and internationally.

Despite the significant improvements we have seen, we know that since the 1990s survival in England has lagged behind that in countries of similar wealth. At a population level, this is manifested in England having amongst the lowest age-standardised incidence rates of rich countries, but amongst the highest mortality rates. Moreover, until 2007³, this deficit had shown little sign of narrowing, other than in breast cancer. This means that fewer people in England survive a diagnosis of cancer than should, a situation that should be regarded as unacceptable.

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. There are many reasons why survival might be lower for older people – 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 age. It will be imperative to develop a better understanding of why we see these differences in order to tailor approaches for older people.

Receiving a cancer diagnosis is not inevitable, and we should be careful not to succumb to the criticism of cancer improvement efforts that "we have to die of something". Although cancer is primarily a disease that affects people at older ages, around half of all cancers are diagnosed in people under the age of 70, and more than a third of all cancer deaths occur before that age. Moreover, cancer is the biggest cause of death from illness or disease in every age group, from the very youngest children to the very elderly. Therefore, notwithstanding the progress we have made, there is a huge amount more to do to avoid premature mortality.

³ Latest international comparison data available



iii) Diagnosis

Efforts to understand international comparisons have led to a broad acceptance that, on average, cancers are diagnosed at a more advanced stage in England than in other comparable countries, which makes them less amenable to curative treatment. The drivers of these international differences are complex but are increasingly understood. We also know that some parts of England achieve better outcomes than others, and that this variability is not simply correlated with deprivation levels. Preliminary evidence suggests that some CCG populations have outcomes for some types of cancer close to some of the best-performing countries, but nowhere does this include all the types of cancer studied.

Diagnosing substantially more cancers earlier could be transformative in terms of improving survival and reducing mortality. For example, when bowel cancer is diagnosed at the earliest stage, more than 9 out of 10 people survive at least 10 years. However, if diagnosed at late stage survival is below 5%; fewer than 1 in 10 people are currently diagnosed at the earliest stage. This picture is mirrored in many other types of cancer. While some cancers grow slowly, many are aggressive and grow very fast, making speed to treatment of the essence. The majority of cancers that are cured require treatment with surgery and/or radical radiotherapy, both of which are only effective on tumours that are localised.

Across England, there is around a two-fold variation in the proportion of cancers diagnosed at an early stage, suggesting significant scope for improvement. Partly as a result of this variation, one-year survival in some CCGs is more than 10% higher than in other CCGs.

Population-based screening currently detects around 5% of all cancer cases; the vast majority are detected following symptomatic presentation by patients. Despite seeing on average only 8 new cases of cancer per year, GPs play a pivotal role. In most cases, patients presenting with symptoms to a GP are referred after the first or second visit. But in around a fifth of cases, particularly with less common cancers or where symptoms are less specific, patients visit their GP three or more times before referral for a diagnostic test. 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.

Whilst improving speed of access to GPs would help, the situation is also compounded by people being reluctant to visit their GP. International studies show that patients in England are more worried and embarrassed about seeing their doctor with a symptom that might be serious than those in other countries.

More than a fifth of all cancers are only diagnosed as a result of an emergency presentation at hospital and these patients have significantly poorer survival.

iv) Treatment

Recent international comparisons have revealed that treatment rates with curative intent are lower in England than in other wealthy countries, particularly for patients with more advanced cancers. Furthermore, there is considerable variability in access to radical



treatment. For example, the latest lung cancer audit indicates a six-fold variation in rates of radical resection across the country. Since surgery is one of the few curative treatment options for lung cancer, this has a profound bearing on survival. It is equally clear that not all services are delivered in accordance with NICE guidance. For example, in some places surgical resection continues to be provided in centres undertaking very few procedures per year.

We increasingly understand 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 responses to treatment, requiring the use of molecular diagnostics to guide therapy effectively. Our evolving understanding will be critical for optimising effective treatment in the future, but 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 costeffective care.

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, other than in a few leading centres, internationally we are viewed as being slower to adopt new innovations, across all treatment modalities, than other countries, even where those innovations are clearly cost-effective and/or were developed within the UK health system. This is despite recent developments designed to address this, such as the Cancer Drugs Fund and investment in advanced radiotherapies such as IMRT and SABR. It affects both the outcomes we achieve, and the attractiveness of England as a destination for inward R&D investment. Faster adoption and dissemination would position the NHS in a much more positive light, as a system which harnesses excellence and views innovation as a tool for delivering productivity and better outcomes, albeit sometimes with increased cost. Nowhere is this truer than in cancer.

v) Patient experience and quality of life beyond diagnosis and treatment

Patients, with the exception of those who believe their diagnosis was unnecessarily delayed, generally have a high level of satisfaction with the hospital care they receive, though there are variations across England and amongst different groups of patients. For example, patients with rare and less common cancers report marginally lower rates of satisfaction than those with more common cancers.

Undoubtedly, the quality of hospital care has, in many cases, improved. However, patients often express frustration with the fragmentation of their care, particularly in some parts of the country, and also with the sporadic and sometimes impenetrable access to information about their diagnosis and treatment. Many patients complain of a lack of information about available support services in the community. Around a fifth of cancer patients say they felt treated like a set of symptoms rather than being recognised as a person. Furthermore, although there is a recognised strong link between a positive, well-engaged workforce and good patient experience, nearly half of NHS staff say they have not received any training on how to deliver good patient experience.



These experiences contribute to a wider culture that the Francis report identified, where pockets of poor care and inadequate dignity and respect still exist and are tolerated. Over the last five years, the Government has worked hard to respond to the Francis inquiry, seeking to transform many aspects of care and highlighting the importance of culture change.

We need to rise to the aspiration set out in the NHS Five Year Forward View that services are integrated around the patient and take account of their differing needs.

We also need to consider the rising numbers of people who have survived cancer, but who may suffer long-term effects from the treatments they have been given, are at greater risk of a second cancer diagnosis, and who may need help returning to a lifestyle of their choosing. For example, a quarter of all cancer patients will have treatment-related long term effects. These can be particularly difficult for certain patient groups, e.g. children treated for cancer. Around a third of cancer patients report that they felt the future side effects of treatment were not fully explained to them.

Around half of people living with cancer have one or more moderate or severe unmet needs, such as depression or anxiety, six months after the end of treatment. Patients also face the combined impact of loss of income plus the additional costs associated with cancer. Identifying and addressing these needs would not only further improve patient experience and quality of life, but there is the potential for medium to long term savings in care and downstream treatment costs.

An estimated 900,000 family members and loved ones provide vital unpaid care for cancer patients. Many do not identify themselves as carers, and are not informed about the support services available to carers, with nearly half saying they receive no support at all.

vi) End of life

Sadly, notwithstanding all the efforts to improve survival, a number of patients will still die from cancer. In 2015, this is estimated at 130,000 patients in England, a number that has not declined since 2000. 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. However, at present, less than a third are able to exercise that choice. We also know that many patients do not have a satisfactory experience at the end of life. For example, only one in five of those with cancer who die at home have complete pain relief all of the time in the last three months of life, compared with just under two-thirds of those with cancer who die in a hospice.



1.2 Why is a new cancer strategy timely now?

NHS staff have coped admirably with a 10% increase in caseload (25,000 additional patients each year) over the last five years, despite no increase in the cancer portion of the NHS budget (approximately 6.5%). Partly as a result, services are now consistently described as being at saturation point, with limited "headspace" to drive improvement.

Moreover, providers, professionals and commissioners agree that cancer services would benefit from greater strategic coherence in commissioning. This would help drive improvements in a number of areas, for example performance by Trusts against the 62 day waiting time target.

Previous cancer strategies have had a profound impact on the improvements we have seen over the past 15 years. The first NHS Cancer Plan, published in 2000, focused primarily on improvements in secondary and tertiary services, which needed both up-skilling and reorganisation. Such improvements were a pre-requisite for addressing challenges in other parts of the patient pathway.

The Cancer Reform Strategy, published in 2007, continued those themes, but also addressed more significantly the opportunities offered by earlier diagnosis and better intelligence. It led to the establishment of both the National Cancer Intelligence Network (NCIN) and the National Awareness and Early Diagnosis Initiative (NAEDI), co-chaired by Cancer Research UK. It acknowledged the imperative of understanding the needs of survivors, establishing the National Cancer Survivorship Initiative (NCSI), co-chaired by Macmillan Cancer Support. It also established the National Cancer Equality Initiative (NCEI) which sought to understand the inequalities in incidence, survival and mortality across different groups, through better data collection and research.

The Improving Outcomes Strategy was published in 2011, against a backdrop of significant planned changes in NHS configuration and commissioning arrangements, as well as a tightening budget. There has, as a result of these circumstances, been a fragmentation of responsibilities and a loss of momentum. Commissioners report that cancer commissioning is too disjointed and strategic clinical networks have not fulfilled the role of cancer networks in coordinating services and driving improvements. Consequently, some of the improvements foreseen in the 2011 strategy have been harder to implement, some having not moved forward at all, and cancer pathways lack coordination, which impacts on care.

The 2015 strategy will seek to address the current landscape, embedding policies and initiatives across the health service. It will:

- Align with the principles set out in the NHS Five-Year Forward View, a vision owned by all six ALBs, and strongly welcomed by most parts of the health community;
- Place stronger emphasis on the "upstream" and "downstream" elements of the cancer patient pathway, with more attention given to prevention, earlier diagnosis and recovery;
- Seek to address the significant variability in access to optimal diagnosis and treatment;



- Acknowledge and plan for the increased demand we will see in the coming years, such that this is addressed proactively (and therefore cost-effectively) rather than reactively;
- Set new levels of ambition for what can and should be achieved, with concerted efforts and an increase in investment.

We anticipate that the key questions that the strategy will address will be outcome-focused, i.e.:

- How should we reduce the growth in the number of new cancer cases?
- How should we save more lives and reduce the number of premature deaths?
- How should we improve quality of life throughout the patient journey?
- How should we improve the efficiency and effectiveness of delivery?
- What should we be planning for and anticipating beyond 2020?
- How much will it cost?
- Who should drive implementation and how should it be monitored?



2. Ambitions for the Next Five Years

We believe that it is appropriate to set high-level ambitions in the new strategy, framed in terms of the outcomes that matter most to patients and to society. These would then be supplemented with a series of supporting metrics, designed to ensure that we are on track to achieve the ambitions.

2.1 Cancer Incidence

There is much that we could do to slow down the relentless rise in the numbers of patients being diagnosed with cancer each year. Increasing incidence places a huge burden on the NHS, but it also places a huge burden on the patients and their families, as they undergo intensive and sometimes debilitating treatment. As one of the key principles in the NHS Five Year Forward View, prevention initiatives need to feature prominently in the next cancer strategy. We believe there is an opportunity to set two ambitions:

- By 2020, we would start to see a discernible fall in age-standardised incidence. As noted above, overall incidence has been rising, and we have also seen a marginal increase (5%) in age-standardised incidence rates over the last ten years. Prevention efforts take time to feed through in to incidence rates, 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. Despite the long-term nature of prevention efforts, declines in smoking rates in past years should start to feed through to a discernible fall in overall age-standardised incidence rates in the coming years.
- **By 2020, adult smoking rates should have fallen much further.** Smoking remains by far the largest modifiable risk factor for cancer, responsible for more than 50,000 new cases per year in England. As such, there is an opportunity to set a specific ambition around future reductions in smoking rates.

2.2 Cancer Survival⁴

2.2 <u>Cancer Survival</u>

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. The strategy could incorporate three ambitions related to survival:

- Increase in 5 and 10-year survival. Surviving for ten years or more following a cancer diagnosis is far more meaningful for patients than one or five years. Cancer Research UK and many experts around the country believe that, with continued progress, it

⁴ There continues to be debate around whether survival or mortality is a better measure of cancer outcomes. However, if we address incidence and survival, mortality is a product of the two. Furthermore, from the perspective of a patient, survival is a more tangible and desirable outcome metric than the avoidance of death. Numbers of lives saved was proposed as a new measure in the 2011 strategy. However, it is almost impossible to assess progress reliably against this measure, not least with regard to prevention efforts.



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%⁵ now, benefitting nearly 100,000 patients per year.

- Increase in one-year survival, with a reduction in CCG variation. Achieving survival one-year from diagnosis is a proxy for long-term survival outcomes and the data is generally available much sooner, meaning that it is easier for commissioners and providers to track progress and assess the impact of interventions. Furthermore, one-year survival will specifically enable us to track progress on earlier diagnosis. 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 to meet those delivering the highest levels of patient outcomes should be possible with a focused effort. Focusing on internal (i.e. England) variations will provide challenge within the NHS and foster professional ownership of the need for change.
- **Reduction in survival deficit for older people.** Recent international comparison data suggests that the deficit in survival rates is even greater for older people than it is for younger age groups in several types of cancer. Moreover, if we are to narrow the gap overall, we will also need to do so with older patients.

2.3 Patient Experience and Quality of Life

Patients' experience of their care should have equal prominence with more clinical measures like survival. In line with the aspirations set out in the FYFV, the NHS needs to move to a more patient-centred service, and increasingly away from one focused around the needs of providers, or the professionals who work for them. It is therefore appropriate to have ambitions that reflect this shift. Three are worthy of consideration:

- Continuous improvement in patient experience with a reduction in variation. In the latest cancer patient experience survey (CPES), 89% of patients said they were satisfied or very satisfied with their care overall. 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. 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 at least every other year, and patient satisfaction should be measured for every hospital.
- Continuous improvement in long-term quality of life. We don't just want people to survive cancer, we want them to lead healthy, fulfilled and productive lives, as far as is possible, after their treatment is complete. To this end the strategy will address the need for a suitable quality of life metric to incentivise the provision of better preventative, rehabilitation and aftercare interventions. It will assess the role of PROMs in this.

⁵ For patients diagnosed in 2010-2011; these data were available in 2014



- A majority of patients assessed as having had a "good" death. For those who do not survive a cancer diagnosis, we need to incentivise the system to ensure those patients 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 a suitable dataset for this care is required to monitor outcomes and ensure effective commissioning. The strategy will suggest how to measure and set an ambition for the proportion of patients who have experienced a "good" death.



3. Key Initiatives In the 2015 Cancer Strategy

The Taskforce charged with developing the 2015 Cancer Strategy has only recently started work and a huge amount of consultation is planned over the coming weeks to determine the best routes to improve outcomes and achieve the possible ambitions set out above. Nevertheless, some aspects of the strategy are already becoming clear, and we illustrate some of those in this section.

The big shifts we might hope to see over the next five years are:

- Greater emphasis on prevention efforts, including secondary prevention;
- A multi-faceted approach to detecting many more cancers earlier, including a stepchange in capacity and a shift in culture around investigative testing;
- Reductions in variability of access to optimal diagnosis and treatment and in inequalities in outcomes;
- Integration of health and social care such that all aspects of patients care are addressed, particularly at key transition points in the system;
- Patients feeling better informed, and more involved and empowered in decisions around their care;
- A system that recognises the critical importance of cancer research and is primed to innovate, with cost-effective technological advances rapidly adopted and plans to embed stratified approaches in all elements of care;
- A system that provides better and more immediate access to data and intelligence, as a key driver of improvement;
- Commissioning based around health and wellbeing outcomes, with a population focus:
- Clearer leadership and accountability for driving improvements, across the system.

3.1 How should we reduce the growth in the number of cancer cases?

The new strategy will call for a significantly greater emphasis to be given to efforts in prevention, building on the commitments set out in the NHS Five Year Forward View (FYFV). Considerable progress has been made during this Parliament in tobacco control, including legislation to ban smoking in cars carrying children and to introduce standardised packaging for cigarettes. This needs to be built upon in the next five years. We will propose a range of measures designed to reduce smoking rates further, with a particular emphasis on groups where smoking rates are still at high levels.

Beyond smoking, cancer prevention will require a combination of population level interventions and individual lifestyle behavioural interventions. They will be focused on helping more people maintain a healthy body weight, supporting more people to eat a healthy, balanced diet, reduce their alcohol consumption and to take regular physical activity, and ensuring fewer people expose themselves to other carcinogens, e.g. excessive UV exposure.

Some of these aspects of individual lifestyle modification will be addressed through the Prevention strategy being developed by PHE, with NHS England involvement, which



proposes an intensive lifestyle change programme for a proportion of the population deemed at high risk. Although currently targeted at reducing cases of diabetes, reductions in obesity and overweight, and improvements in diet, coupled with increases in physical activity, will also result in fewer cases of cancer in the future. As such, the cancer strategy will consider whether this new Prevention strategy needs to be broader in scope and ambition.

Prevention efforts can also be boosted by screening that detects and offers the ability to remove pre-cancerous lesions, as is the case with the cervical and bowel screening programmes. The cancer strategy will propose efforts to increase uptake of bowel screening along with roll-out of the new faecal immunochemical (FIT) test and completion of the Bowelscope roll-out by 2016. Primary human papilloma virus (HPV) testing for cervical cancer prevention should also be implemented rapidly, assuming current pilots are successful.

Furthermore, chemo-prevention, particularly for breast cancer and HPV vaccination for cervical and head and neck cancers are already being used judiciously and have the potential to further reduce the numbers of people who develop these cancers in the years ahead. In some of these cases, there is currently considerable variability in uptake, the reduction of which could significantly improve outcomes. The strategy will assess ways in which uptake can be improved.

The cancer strategy will also propose approaches to improve secondary prevention, i.e. reducing recurrence through initiatives such as rehabilitation and physical activity.

3.2 <u>How should we save more lives and reduce the number of premature</u> deaths?

3.2.1 <u>Earlier Detection and Diagnosis</u>

The new strategy will propose a range of actions designed to speed up cancer detection and reduce the numbers of patients whose cancers are advanced at the point of diagnosis. This will be reliant on regular monitoring of the distribution of stage at diagnosis and the number of diagnoses that result from an emergency presentation.

At the heart of the strategy will be proposals designed to streamline the diagnostic pathway for patients and reduce the burden of diagnosis-related visits on GPs. The ACE programme (Accelerate, Coordinate and Evaluate), currently being implemented jointly by NHS England, Cancer Research UK and Macmillan Cancer Support, will test new pathway models to speed up diagnosis. One example is the concept of multi-disciplinary diagnostic testing facilities for vague or unclear symptoms, which could be commissioned either in the community setting or within secondary care facilities. Following evaluation of the ACE pilots, the strategy will propose a process for roll-out of those models which are shown to be effective from 2016/17. The strategy will also consider whether a broader range of triage tests should be provided within the primary care setting, such as newly emerging point-of-care tests for several types of cancer.



The strategy will provide clear direction on the need for continuation of PHE investment in "Be Clear on Cancer" campaigns, designed to encourage patients to visit their GP if they have persistent symptoms which could be cancer, and not be worried or too embarrassed to do so.

As the strategy is developed it will explore the feasibility of a single-tier system for referral of patients with suspicious symptoms. It will explore how quickly testing is carried out currently when a "non-urgent" pathway is followed⁶, to consider whether a two-tier system adds unnecessary complexity. The strategy will consider whether all referrals for testing for possible cancer should be regarded as urgent.

Coupled with this will be a higher level of focus on late presentation at CCG level. We will consider whether CCGs should be required to develop local action plans to improve the proportion of patients diagnosed at early stage, and to undertake an audit of cancers diagnosed as a result of an emergency presentation (EP) to determine what lessons can be learned for the future. Ideally, patients would be able to feedback on their EP-diagnosis experience, to understand their perspective on whether diagnosis could have been speeded up.

Furthermore, new NICE guidelines, reducing the threshold of suspicion which would trigger a referral with cancer symptoms to 3%, will be introduced subject to the outcome of ongoing consultation. The strategy will consider how best to communicate these guidelines clearly and whether tools should be provided to make them easier to use by GPs.

Efforts are being made to increase the numbers of GPs in training. However, system changes for earlier diagnosis also need to reduce, where possible, the number of repeat GP visits required. For example, it will identify whether strategies such as telephone triage by GPs could expedite referral. CCGs might also consider how they can facilitate more regular discussions between primary and secondary care, to optimise referral pathways. In areas where GP access is particularly poor, it may be appropriate for commissioners to consider pathways for patients to self-refer to diagnostic facilities.

The strategy will explore the need for plans to introduce risk based screening programmes, taking into account the development of the knowledge base around genetic and other risks. Further developments of the existing national screening programmes will be considered on their merits.

Finally, progress in earlier diagnosis will depend on a significant investment in increasing diagnostic capacity, currently under-provided across a range of diagnostic tests. Some of this will require efforts to increase the workforce, which by nature requires a long-term solution. Short-term measures will be proposed to alleviate capacity constraints for the next five years.

3.2.2 <u>Treatment</u>

The strategy will consider which aspects of treatment might benefit from further centralisation and specialisation, and which might be further devolved, including the

⁶ Currently it is estimated that 90% of patients referred on a non-urgent pathway are seen within 4 weeks



possibility of treatment and care at home. Subject to seeking the views of patients, we will test and develop solutions designed to ensure better connectivity and shared protocols between providers. A key driver will be reducing national variability, ensuring that more places deliver to accepted standards of care.

We will need to explore workforce capacity and capability, as well as provision of specialised equipment, to ensure the English NHS is at the head of the curve. The new strategy will make recommendations for capacity, including workforce, across all treatment modalities necessary to address the growing numbers of cancer diagnoses projected in the years ahead. Over and above this, the strategy will propose a process for replacing the now ageing radiotherapy equipment installed base, and for keeping this technologically and numerically up to date in the future. Aligned to this, the taskforce will assess how to ensure we are in a position to further innovate in the area of radiotherapy, through a combination of clinical trials and enhanced evaluation programmes, ultimately leading to the faster adoption of new techniques.

The strategy will propose the adoption of a sustainable, long-term solution to the commissioning of medicines, including a strategy to improve the current operating model of the Cancer Drugs Fund, including making sure that it is more effectively aligned with NICE processes. This new model will propose ways in which we can be faster at adopting new innovations, whilst retaining the imperative of cost-effectiveness.

The strategy will explore emerging data on the reasons behind poorer access to diagnosis and treatment for older patients and will outline opportunities for improvement. We want to ensure that age is not used as a proxy for frailty and that all older patients receive an appropriate assessment to inform their treatment decisions.

Finally, the strategy will consider the need for establishment of a national system for the molecular diagnosis of cancer, to ensure patients are receiving the treatments that they will benefit from.

Critically, the Taskforce will work alongside the Taylor Review, to set out ways in which innovation and research developments in all treatment modalities for cancer can more rapidly become routine clinical practice. This will benefit all disease areas, and hopefully help to overcome the NHS' international reputation as a health system which is slow to adopt and disseminate new innovations.

3.3 How should we improve coordination of care and quality of life throughout the patient journey and beyond?

The strategy will set out how patient experience and quality of life can be maintained and improved.

First and foremost, the strategy will propose that patients are increasingly regarded as equal "partners" in their treatment and care. They should be supported to take control by being involved in decisions about their treatment and care, viewed as 'experts by experience', and supported to self-manage. Greater transparency will support this. Through workshops over the coming months, we will ask cancer patients for views on providing email addresses at



the point of confirmed diagnosis, to enable more speedy communications and with a view to patients having online secure access to their entire cancer treatment record, from diagnosis onwards. Furthermore, we will ask patients for their views on access to correspondence about their care, for example whether all letters regarding a patient between providers should be immediately copied to the patient.

The strategy will consider ways in which NHS England can work with charities and other bodies to develop better systems to help patients navigate their way through the often mind-boggling complexity of treatment pathways and the options open to them. This would include transparent data on hospital outcomes and available support services in the community and what patients can do to help themselves.

The strategy will set out how the NHS can better support patients. Evidence shows that the support of a Clinical Nurse Specialist (CNS) is vital to people reporting good experiences of care, but there is variation in people's ability to access this support. The CNS workforce gap is widely acknowledged and will continue to grow as the number of people with cancer increases. The strategy will consider how the workforce can best be deployed to effectively support patient care, and what support and training the workforce will need to deal with the changing nature of cancer.

The strategy will also propose that, on completion of their treatment, patients should receive a sufficient package of interventions designed to support them through their recovery, which would include a care plan. The care plan would be constructed jointly with the patient, ideally working with a clinical nurse specialist, and would be owned by the patient and shared with their GP. This plan would include advice on lifestyle to reduce the risk of further cancers, aspects of rehabilitation such as regular exercise, the management of any likely side effects of treatment, as well as awareness advice regarding possible markers of recurrence. Self-management would be the driving philosophy, with appropriate support and rapid access back into the system if required. It is likely that an agreed plan with regular review could be cost-saving in the long-run, as well as enabling the patient to feel they are "back in control".

The strategy will consider how primary and community care (including that provided by local government) can be strengthened to support people to live well at home. A patient with cancer needs their mental health and social care coordinated around them, ensuring that they are not only treated from a medical point of view, but that they are also supported emotionally and practically, helped to get back to work and supported to deal with the financial consequences of a cancer diagnosis.

The strategy will address how best to drive the roll out of risk-stratified pathways of care, which could offer an alternative to traditional follow-up appointments, using remote monitoring, supported self-management and rapid re-entry pathways. Benefits of this stratified pathway approach might include better patient experience, and more efficient utilisation of resources.

Finally, the strategy will address how to ensure that terminally-ill patients are supported to die with dignity and with their end of life care preferences met, drawing on work from the End-of-life Care Choice Review led by the Department of Health, Macmillan Cancer Support, Marie Curie and others.



3.4 How should we improve the efficiency and effectiveness of delivery?

The strategy will make a number of proposals designed to improve the efficiency and effectiveness of delivery of services at a local and national level. The underlying premise will be that most services should be designed through local networks but with national oversight, with commissioners, clinicians and patients encouraged through these networks to engage in an ongoing process to configure services to best meet the needs of the area population. Proposals will consider:

- The appropriate size of area;
- Which services should still be commissioned and organised nationally;
- The role of Strategic Clinical Networks and Academic Health Science Networks;
- How best to improve primary and secondary care integration and access to specialist advice by primary care physicians;
- The future role, organisation and management of peer review.

Critically, the strategy will make recommendations in three additional areas which have hampered improvements to the quality of services in the past:

- Improvements to workforce planning, across all professional groups relevant to cancer;
- Access to data and intelligence, in particular making better use of and linking existing data sets, as well as developing new data sets where these do not yet exist;
- The role of assurance processes in driving improvement.

The strategy will consider whether screening should continue to be jointly overseen by NHS England and PHE, or whether it is better to move total responsibility for screening to one or other organisation.

We anticipate that the strategy will set out initiatives that will have broader benefits to the health service outside of cancer care; we will point out where these opportunities exist and signpost to other relevant programmes of work.

3.5 What should we be planning for and anticipating beyond 2020?

The strategy will highlight a number of areas, currently the subject of research, which will likely yield conclusions beyond 2020, but for which planning might need to commence within the next five years.

The strategy will also propose mechanisms for ensuring that the NHS evolves to be able to accommodate the changing nature of clinical trials, ensuring that as many patients as possible have the option to take part, and that clinical research (including population studies) is adequately supported by the NHS.



3.6 How much will it cost?

Over the next few months, the taskforce will chart out the highest priority investment opportunities, with the aim of improving quality and outcomes. The strategy will indicate the cost of implementing the proposed actions and suggest ways in which existing investment could be better directed.

3.7 Who should drive implementation and how should it be monitored?

Finally, the strategy will propose mechanisms through which national oversight could be better provided, to overcome fragmentation, and to ensure that all services are focused on and supported to deliver continuous improvements in quality.

Harpal S Kumar On behalf of the Cancer Strategy Taskforce March 26, 2015