

Cancer Strategy 2015-20

Cancer Research UK response to the Cancer Taskforce

February 2015

Cancer Research UK (CR-UK) welcomes the opportunity to input to the development of a new cancer strategy for England. We support the World Health Organisation position¹ that cancer plans are vital. They set direction and make the best use of resources over a long time period to reduce cancer incidence and mortality. To continue to improve cancer outcomes, and to make our outcomes among the best in the world in the coming years, we need to maintain comprehensive cancer plans that incentivise action and dedicate resource to beating cancer.

Cancer outcomes in the England still lag behind other comparable countries. Vast improvements are needed to ensure our cancer outcomes become the best in the world; high quality NHS cancer services and a supportive research environment are central to this.

CR-UK wants to accelerate progress so that three in four people survive their cancer for 10 years or more within the next 20 years – a goal that should be supported through an ambitious new cancer strategy. We welcome the vision set out in the Five Year Forward View (5YFV), with particular focus on improving cancer outcomes through better prevention, early diagnosis and access to treatments. The development of this strategy provides an opportunity to build on the ambitions set out in the 5YFV and the previous cancer plan, to set out a clear direction, with associated investment and resource that enables the NHS to provide patients with the best possible outcomes.

Below we have set out three clear commitments we would like to see reflected in the strategy, followed by further detail around how to achieve these. Our comments on barriers to improving cancer outcomes, the need to support research in the NHS and improving data and information are also included. Additional information can be seen in **Appendices A to C**.

Overview

Key commitments CR-UK would like to see reflected in the strategy:

1. **Prevention (pages 3-7):** A shared ambition to reduce the incidence of cancers attributed to lifestyle and environmental factors. This should include strategic investment in service delivery and a long-term commitment to initiatives which address deep-rooted inequity in public health. This includes:
 - I. An ambition and a vision toward a **tobacco-free** UK i.e. less than 5 per cent adult smoking prevalence within the next 20 years; addressing smoking related health inequalities; and comprehensive tobacco control policies with associated investment.
 - II. Commitments to develop a comprehensive **alcohol** harm reduction strategy; an **obesity** strategy and a **skin cancer** prevention strategy.
 - III. Increase Human Papilloma Virus (HPV) vaccine uptake and broaden target groups in-line with the Joint Committee for Vaccinations and Immunisations recommendations.
2. **Early diagnosis (pages 8-11):** To substantially decrease the absolute number and proportion of cancers diagnosed at a late stage¹; increase the proportion of cancers diagnosed at an early stage²; and reduce variation and inequalities in stage of disease at diagnosis across England. This includes:
 - I. Improving uptake and reducing variation in uptake to the **bowel screening** programme and timely introduction of new, evidence-based screening programmes or modifications. For example, considering the evidence for ovarian and lung cancer screening programmes.

¹ Based on known stage

² Based on known stage

- II. Commitment to maintaining evidence-based **public awareness campaigns**, with a particular focus on addressing inequalities.
 - III. Improved mechanisms to get patients into and through the health system quicker to facilitate **swift diagnosis**.
3. **Treatments (pages 12-16):** Substantially reduce variation in access to all effective cancer treatments, and to ensure all patients receive the best, evidence-based treatments available for their condition. This includes:
- I. **Reducing the variation in access to cancer surgery**, particularly in older people; supporting and adopting surgical innovation; and developing valid quality measures for cancer surgery.
 - II. A sustained programme of investment to **modernise radiotherapy services**, including bringing equipment up to date; reduce variation in access to advance radiotherapy techniques and swiftly adopt new innovations; and improve radiotherapy data.
 - III. **A long term solution to funding of chemotherapy and cancer drugs**; an NHS that is ready to deliver personalised medicines and provides all patients with the best medicines for their condition – including adequate and equitable access to molecular diagnostics testing; and support for better chemotherapy data and informatics.

We would also like to see concerted effort in the following areas:

- **Quicker adoption** of new, evidence-based technologies at all points along the cancer patient pathway.
- Tackling the major barriers to improving outcomes (pages 17-18). We would like to see the strategy:
 - Call for **greater investment** in NHS cancer services;
 - Build on current moves in NHS England to increase capacity dedicated to improving cancer outcomes, by setting out the development of a recognised **cancer leadership team** across all health bodies - NHS England, Public Health England and the Department of Health – to provide national oversight and a truly coordinated approach to cancer leadership;
 - Clarify commissioning responsibilities for cancer services;
 - **Address workforce shortages** in diagnostic and treatment services particularly; and
 - **Remove perverse incentives** that support suboptimal care and don't encourage uptake of innovations.
- **To support clinical research** on cancer in the NHS we would like the strategy to (pages 19-20):
 - Support the development of a research strategy, to include all major partners to ensure that research is embedded at all levels of the health service;
 - Commit the NHS to meeting the Excess Treatment Costs (ETCs) of all forms of cancer trials running in the NHS, in accordance with the Health and Social Care Act 2012, the NHS Mandate, Health Service Guidance agreement, NHS constitution and AcoRD guidance.
- **To improve NHS data and patient information**, we would like the strategy to (pages 21-23):
 - Drive up overall data quality through improved and sustainably resourced informatics – including sufficient capacity to analyse and interpret data to inform commissioning of cancer services;
 - Improve data transparency and public access;
 - Improve data on screening, treatments and patient experience; and
 - Address the information needs of patients, including the development of individualised patient information as personalised treatments become more prevalent.

Cancer Prevention

Cancer Research UK (CR-UK) would like to see a commitment in the cancer strategy to:

A shared ambition to reduce the incidence of cancers attributed to lifestyle and environmental factors. This should include strategic investment in service delivery and a long-term commitment to initiatives which address deep-rooted inequity in public health.

Overview

More than 40 per cent of all cancers diagnosed in the UK are attributable to lifestyle and environmental factors.² In recent years the importance of addressing rates of cancer through mitigation of these influencing factors has been increasingly recognised, but so far without the scale of action needed.

We support the focus on prevention, both as an effective - and cost-effective - strategy for addressing ill health as set out in the NHS 5YFV.³ Variations in the trends among the most prevalent lifestyle risk factors for cancer demonstrate both the challenges faced, and opportunities to be exploited, by a comprehensive cancer strategy. Smoking rates have declined in a long-term downward trend. In contrast, rates of obesity have risen markedly in recent years and alcohol consumption remains above historic levels. In practice this means that one in five adults still smoke; a third of people drink too much alcohol; a third of men and half of women don't get enough exercise; and almost two thirds of adults are overweight or obese.⁴

As the number of long-term cancer survivors grows there will also be an increasing need to promote the importance of healthy lifestyles in those populations to prevent new cancers from occurring. The role of lifestyle in preventing cancer recurrence needs further research. There is some evidence for a link with physical activity⁵, but not yet enough to make firm recommendations to patients. The health system must use evidence as it emerges to formulate strategies for secondary prevention.

In addition, chemoprevention approaches have the potential to prevent more cancers, and drugs such as tamoxifen⁶ and anastrozole⁷ have been shown to effectively prevent breast cancer in high risk groups. At the wider population level recent research shows that long term daily low-dose aspirin taken by people in their 50's-60's could help prevent cancers such as bowel, stomach and oesophageal.⁸ However, more research is needed to accurately predict those people who might be at risk of side effects such as bleeding or strokes. As further research around this area develops, it is crucial that the NHS adopts new practice where evidence has shown patient benefit.

Whilst we are encouraged that the NHS will take a more central role in prevention, local authorities now have greater responsibilities for public health. Modelling by the Local Government Association predicts that a funding gap in local government expenditure, opening up in 2015/16, could grow to £12.4 billion by 2019/20. This means that (a) more will need to be done with less and/or (b) alternative funding avenues will need to be sought to maintain public health service provision.⁹ The impact on stop smoking services, health promotion and behaviour-change campaigns, the provision of exercise and leisure facilities must be managed responsibly to the backdrop of these funding pressures. Further information on prevention can be seen in **Appendix A**.

Tobacco Control

Latest data for England show that cigarette smoking prevalence in adults stands at 18.5 per cent¹⁰, continuing a long-term downward trend. Despite this progress, smoking remains the leading cause of preventable death and disease in England – responsible for 81,400 deaths.¹¹ Although smoking is most often associated with lung cancer, heart and respiratory diseases, there is significant impact on wider cancer burden, with smoking linked to at least 13 other cancer types. There is also growing evidence that smoking not only impacts cancer risk but also response to treatments and patient survival.

Research highlights that the total cost of tobacco use to society in England is £12.9 billion a year.¹² By comparison, tobacco receipts for 2013/14 were £9.5 billion.¹³ It is estimated that around £380 million a year is being saved by the NHS as a result of public health strategies such as the ban on tobacco advertising and the creation of stop smoking services which have resulted in fewer people smoking.¹⁴ Although there are challenges to overcome, successful tobacco control policy can save a significant number of lives and help relieve health services of significant financial pressure.

The emergence of electronic cigarettes (e-cigarettes) creates new opportunities for strategies to tackle both tobacco use and nicotine dependence. Significant and sustained investment will be necessary to provide answers regarding the safety, efficacy and long-term impact of these new products. Key aspects we would like to see in the strategy are:

1. A shared ambition and a vision toward a tobacco-free UK (with less than 5 per cent adult smoking prevalence), supported by all political and public health stakeholders.

Linear modelling suggests that by 2020 smoking prevalence in England should fall to just over 13 per cent.¹⁵ With the dramatic decline in smoking rates across the UK over the last 40 years, catalysed by health information campaigns and tobacco control policies¹⁶, politicians increasingly recognise the momentum behind tobacco denormalisation. Responding to the publication of the NHS 5YFV, there has been support across the political spectrum echoing the aspiration for a 'smoke-free Britain'.^{17,18} To support this aspiration, the strategy should commit to:

- An ambition for a 20-year tobacco free society, with less than 5 per cent adult smoking prevalence, and a shared vision for a child born today to reach adulthood in a tobacco-free environment;
- Implementation of a comprehensive five-year tobacco control strategy for England, based on the recommendations of the '*Smoking Still Kills*' report, produced by Action on Smoking and Health; and
- Demonstrate leadership to ensure obligations and guiding principles of the WHO Framework Convention on Tobacco Control (FCTC) are met, including implementation of the measures in the revised Tobacco Products Directive and standardised packaging of tobacco products.

2. Address smoking related health inequalities

Inequalities must be at the heart of any strategy to address the detriment of tobacco use. While much of the focus has – and should continue to be – on socioeconomic inequality, smoking related inequalities exist by gender, sexual orientation¹⁹, level of education²⁰ and also disproportionately persist among those with mental health^{21,22} and substance abuse issues.²³

Research by CR-UK and the National Cancer Intelligence Network has demonstrated that economic inequality is linked to around 15,000 extra cases of cancer and around 19,000 extra cancer deaths every year in England.²⁴ Over half of those deaths, 11,000 each year, were due to lung cancer. Eighty six per cent of lung cancer cases in the UK are attributable to tobacco.²⁵ Incidence of lung cancer is strongly related to deprivation and there is a clear trend of increasing rates with increasing levels of deprivation in the UK.²⁶ A strategy to reduce smoking related health inequalities should include the following:

- The implementation of a minimum consumption tax for tobacco products, as consulted in 2014, coupled with a tax escalator on cigarettes of 5 per cent above inflation and 10 per cent above inflation for hand rolling tobacco;
- Sustained support for smoking cessation programmes to ensure that 'gold standard' NHS stop smoking services are available and delivered to support all smokers interacting with the services; and

- The introduction of a register of tobacco retailers in England, coupled with the disclosure of tobacco company sales data. These data are needed to evaluate the relationship between density of retailers, patterns of tobacco sales (by product and price category) and smoking related health inequalities, particularly in relation to socioeconomically deprived communities.

3. Comprehensive tobacco control policies must be coupled with investment in tobacco control initiatives at a national and local level

Positive commitments from local authorities to comprehensive tobacco control programmes must be matched with the investment needed to ensure they can provide smokers with 'gold standard' stop smoking services. A quit smoking attempt with NHS stop smoking services is around three times likelier to be successful than attempting to stop unassisted.^{27,28} Funding for, and investment in, tobacco control should be achieved through the following:

- The introduction of a financial levy for tobacco manufacturers and importers, hypothecated for the provision of public health in particular, stop smoking services and tobacco control mass media campaigns.
- Funding for the responsible agencies to effectively tackle the illicit tobacco trade and enabling the UK to meet the requirements of the *Illicit Trade Protocol*²⁹ - which should be ratified without delay.
- Investment to ensure that local authorities are sufficiently resourced to guarantee delivery of standards consistent with NICE guidance.^{30, 31, 32}

Alcohol

Alcohol consumption remains a serious risk factor for cancer. It is associated with seven cancers (mouth, throat, food pipe, voice box, breast, bowel, and liver) and in the UK is linked to 12,800 cancers a year.³³ Despite being well established as a risk factor for cancer³⁴, more action is needed to reduce alcohol related cancers.

As well as the impacts on health, alcohol harms place a significant burden on the economy and the NHS. The Government claim that the total cost of alcohol to society is £21bn a year.³⁵ The direct cost to the NHS is estimated to be £3.5bn a year³⁶ and the cost of alcohol related cancers alone is estimated at £728m.³⁷

There is no level of drinking which is free from the risk of cancer. As little as one standard drink a day (such as a standard 175ml glass of wine) can increase the risk of breast cancer among women and mouth, throat and food pipe cancers.^{38, 39} Reducing alcohol consumption is therefore a necessary part of cancer prevention strategies. CR-UK strongly supports initiatives and measures to reduce alcohol consumption, particularly that which exceeds the NHS lower risk guidelines.⁴⁰ We would like the strategy to commit to:

1. The development of a comprehensive alcohol harm reduction strategy

Successful alcohol strategies require national leadership and a commitment to reduce total alcohol consumption among drinkers. A comprehensive alcohol strategy should be based on the independent Health First report.⁴¹ This strategy part-funded by CR-UK, identifies the key policies needed to reduce alcohol harm. These policies are not only supported by the evidence but are consistent with the NICE Guidance.⁴²

Despite the concerns about alcohol and cancer only a third of people in Great Britain were able to identify drinking frequency as a risk factor for cancer.⁴³ But there is evidence that the inclusion of health warnings on alcohol products increases consumers' knowledge and awareness of the adverse health impacts of alcohol.^{44 45} A new comprehensive alcohol harm reduction strategy should include:

- Measures to tackle the price, marketing and availability of alcohol as detailed in *Health First*⁴⁶;
- Better health information on alcohol products; and

- Sustained funding for evaluated health marketing campaigns.

Obesity, Poor Diet & Physical Activity

Being obese and overweight is a significant cause of cancer and is associated with over 18,000 cases of cancer in the UK.⁴⁷ Obesity represents a serious and growing threat to the NHS. It is specifically linked to bowel, womb, oesophageal, pancreatic, kidney, gallbladder and breast cancer in women after the menopause. Currently it is estimated that excessive weight costs society £16bn⁴⁸ and the NHS £5.1bn directly.⁴⁹ Obesity related cancers alone are estimated to cost £200m, although this is likely to be an underestimate.⁵⁰

The UK is among the worst performers on obesity in Western Europe. It is estimated that 67 per cent of men and 57 per cent of women over the age of 20 in the UK are overweight or obese.⁵¹ This is much higher than the average in Western Europe of 61 per cent and 48 per cent respectively. Although obesity rates among children may have reached a plateau in England, they remain very high with one third of year 6 children in England being classed as overweight or obese.⁵² Among adults the current trend is more concerning. In England, the proportion of adults that were overweight or obese 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 2013.⁵³ We would like the strategy to commit to:

1. The development of a comprehensive obesity strategy

The Government should develop a new comprehensive strategy for tackling obesity. This should focus on tackling the drivers of an unhealthy diet and encouraging people to be more physically active. This means both empowering people at the individual level and tackling the obesogenic environment.

It is also important to continue to increase awareness of the health risks of obesity and poor diet. Change4Life is a successful brand in engaging the public. It is important that it continues to be evaluated to ensure that it both increases awareness of the harms of poor diet and lack of physical activity and leads to behaviour change. A new comprehensive obesity strategy should include:

- Measures to tackle the drivers of unhealthy diets such as unhealthy food marketing; fiscal measures and improving the availability of healthy food;
- Measures to promote physical activity; and
- Continued investment and evaluation of Change4Life.

Ultraviolet (UV) Radiation and Human Papilloma Virus (HPV) prevention

We would like the strategy to commit to:

1. The development of a national skin cancer prevention strategy

Malignant melanoma is the 5th most common cancer in the UK, and more than 80 per cent of cases are caused by excessive UV exposure.⁵⁴ In 2011, there were around 13,300 new cases of malignant melanoma in the UK and around 2100 deaths in 2012.^{55,56,57, 58} Unlike other risk factors for cancer, UV radiation only increases the risk of skin cancers. Comprehensive skin cancer prevention strategies have been shown to be effective in reducing excessive UV exposure and reducing incidence of melanoma.⁵⁹ Therefore a comprehensive approach towards skin cancer prevention should be developed, tackling the main behaviours that lead to overexposure to UV radiation, including:

- Sustained funding for national mass media campaigns on sun awareness and behaviour change;
- Tools and guidance to reduce excessive sun exposure, especially among outdoor workers and at-risk groups; and
- The introduction of further regulations of sunbed businesses as set out in the Sunbed (Regulations) Act 2010.

2. Efforts must be made to increase HPV vaccine uptake and broaden target groups in-line with JCVI recommendations

HPV is an important preventable risk factor for cervical cancer, other anogenital cancers, and head and neck cancers. The HPV vaccination programme has been a big success - in England between 2013 and 2014, 86 per cent of year 8 girls received all three doses of the HPV vaccination.⁶⁰ However, there are areas where vaccination rates are less than 80 per cent.

The Joint Committee on Vaccinations and Immunisations (JCVI) has recommended vaccination for men who have sex with men, and is looking to develop a practical and cost effective approach to this. They are also investigating whether it is cost effective to vaccinate all boys at age 12-13 (year 8). It is important that Government follows the JCVI's recommendations and ensure that they are incorporated into any future tendering process for HPV vaccines. HPV prevention should focus on the following policy initiatives:

- Continuing to encourage take-up of the HPV vaccine particularly with an emphasis on areas or population groups with lower than average take-up;
- Implementing the recommendations of the JCVI on offering the HPV vaccination to boys and men who have sex with men.

Early Diagnosis of Cancer

Cancer Research UK (CR-UK) would like to see a commitment in the cancer strategy to:

Substantially decrease the absolute number and proportion of cancers diagnosed at a late stage³; increase the proportion of cancers diagnosed at an early stage⁴; and reduce variation and inequalities in stage of disease at diagnosis across England.

Overview

If England's cancer survival rates are to match the best in the world, it is essential that the disease is diagnosed at a stage when treatment is more likely to be successful. There is some evidence of later stage diagnosis in the UK compared to other countries, notably for lung and colorectal cancer.^{61, 62} In addition, almost a quarter of newly diagnosed patients in England still received their diagnosis through an emergency route, often at an advanced stage.⁶³

In line with our role as a partner in the National Awareness and Early Diagnosis Initiative (NAEDI), early diagnosis is an organisational priority for CR-UK. NAEDI was established to coordinate and provide support to activities and research across the diagnosis pathway. This includes public awareness and response to health changes, and support for primary care - particularly GPs, to facilitate earlier diagnosis.

There has undoubtedly been a significant increase in the number of patients being referred via the two-week wait (urgent) referral pathway in recent years, from 900,000 in 2009-10 to over 1.4 million in 2013-14 – an increase of over 50 per cent.⁶⁴ However, this is not a straightforward success; changes in referral patterns are likely to be – at least in part – due to both (a) rising cancer incidence linked to the ageing population and (b) the fact that this referral pathway was under-used in the past

NAEDI has done much to drive efforts to secure earlier diagnosis of cancer since the publication of the last cancer strategy. However, we often diagnose cancer later in England than in other comparable countries, and there is geographical variation and other inequalities in stage at diagnosis across the country. It is important to understand the underlying reasons for this variation to address it.

It is essential that a concerted effort to diagnose cancers early continues to be made; NAEDI's aim to promote earlier diagnosis, working across the patient pathway, is as important as ever if we are to prevent avoidable deaths from cancer. Not only does this have the potential to improve the lives of many cancer patients, there is also some evidence that earlier diagnosis could save the NHS money through averting the costs associated with treating cancer at a more advanced stage. For example, research has suggested that achieving the level of early diagnosis comparable with the best localities in England for the cancers featured (colorectal, non-small cell lung and ovarian) could provide treatment savings of over £44 million, benefitting nearly 11,100 patients.⁶⁵

Screening

England's cancer screening programmes save lives. It is important that the programmes are regularly reviewed to ensure the most evidence-based and cost-effective technologies are used and that implementation of the programmes is optimal. The NHS must continue to provide evidence-based, balanced information that enables members of the public to make an informed choice about whether to accept their screening invitation.⁶⁶

Screening programmes also require strong national leadership, and clarification of how this will be maintained, with the loss of PHE's director of cancer screening programmes, is needed. We would also like to see

³ Based on known stage

⁴ Based on known stage

transparency and clear communication of the division of screening responsibilities between NHS England and PHE. Key aspects we would like to see in the strategy are:

1. Greater efforts to diagnose bowel cancer earlier through screening

Bowel cancer is the fourth most common cancer in the UK and the second biggest cancer killer.⁶⁷ Uptake of bowel screening across England is lower than the other screening programmes - at 58 per cent - and there is significant variation across the country, with 66 per cent uptake in the highest performing areas compared with 42 per cent in the lowest.⁶⁸

We also know that there are significant barriers to the roll out of bowel scope into the screening programme which has been delayed. Bowel scope has the potential to significantly reduce bowel cancer incidence and mortality⁶⁹, so it is essential that it is rolled out as swiftly and effectively as possible. We are undertaking a piece of policy research to understand how best to achieve this and the findings should be incorporated into national plans.

- Evidence-based improvements in the endoscopy service should be implemented to ensure demand can be met, including the full roll out of bowel scope as soon as possible, as committed to in *Improving Outcomes: A Strategy for Cancer*;
- The Faecal Immunochemical Test (FIT) should replace the Faecal Occult Blood Test (FOBT) as the bowel screening programme's primary test in a timely manner, subject to the findings from a pilot expected to report in spring 2015^{70, 71, 72, 73};
- Inequalities in bowel screening uptake must be addressed and overall uptake improved, subject to informed choice;
- GP involvement in the bowel cancer screening programme should be encouraged.^{74, 75} This may include ensuring that GPs are informed of all patients invited for screening and non-responders, able to provide test kits, and/or more training is provided for wider practice staff on opportunities to have conversations with patients and simple actions they can adopt in their practice; and
- Uptake data from the bowel screening programme should be published regularly, in line with the other cancer screening programmes.

2. Introduce HPV testing into the cervical screening programme

- HPV testing should be introduced as the cervical screening programme's primary test in a timely manner, subject to the pilot's findings.⁷⁶

3. Timely introduction of new, evidence-based screening programmes/modifications

- New screening programmes and modifications should be introduced in accordance with the evidence-based decisions of the National Screening Committee (NSC). This includes for lung and ovarian cancers, the evidence on each of which is due to be considered by the NSC in 2015.
- The impact of new screening programmes and/or programme modifications should be modelled to adequately plan for their implementation in conjunction with all necessary stakeholders (to ensure the appropriate levels of equipment, workforce, etc. exist in the system to facilitate roll out).
- Evidence relating to the potential of risk-stratification in screening should be evaluated, including frequency and nature of testing, but also with respect to providing information.

Public facing awareness raising campaigns

The Be Clear on Cancer (BCoC) campaigns have been successful in raising awareness of the key signs and symptoms of a range of cancer types among the general public, and have contributed to behaviour change on

the part of both patients and health professionals. For example, the evaluation of the first national lung BCoC campaign showed that 700 extra patients were diagnosed with lung cancer, and 300 more received potentially life-saving surgery, compared with the same period in the previous year.⁷⁷ Key aspects we would like to see reflected in the strategy are:

1. A commitment to maintaining evidence-based public awareness campaigns, with a particular focus on addressing inequalities.

- Perceived barriers of not wanting to waste doctors time⁷⁸ and other important barriers to help-seeking must be addressed.
- There should be greater alignment in messaging (i.e. between NHSE, PHE, and campaigns such as 'choose well') to limit mixed messages to the public and ensure there is clarity about the actions people can take.
- Greater/better integrated working between national and local PHE, Local Authorities and Health and Wellbeing Boards to tailor the delivery of national campaign activity to local audiences (and support tackling of inequalities).
- The concept for extending 'making every contact count'⁷⁹ should be explored to include early diagnosis.
- Campaigns must be consistently and robustly evaluated, including assessments of cost-effectiveness and impact on clinical outcomes.
- The impact of campaigns in terms of increasing or reducing inequalities should be reported and for this to factor into decision making on which campaigns to develop or run.⁸⁰

Optimising clinical practice and systems

GPs only see 8 or so new patients with cancer each year and it is difficult for them to know all the signs and symptoms of more than 200 types of cancer. It is therefore essential that GPs are supported in their roles and that the health system is flexible enough to allow them to diagnose cancer earlier. CR-UK is a partner in the Accelerate, Co-ordinate, Evaluate (ACE) programme which aims to support NHS organisations to implement best practice in early diagnosis - with pilots exploring innovative pathways to diagnosis such as straight to test endoscopy- and it is important that the findings of the ACE programme are rolled out across the NHS as appropriate. Key aspects we would like reflected in the strategy are:

1. More support for GPs to refer patients effectively

- Tools (such as the Cancer Decision Support Tool) and training should be co-ordinated to support GPs to understand and reflect on their current referral behaviour and to help them identify early signs of cancer and promptly refer.
- The evidence base and impact of the introduction of new NICE urgent referral guidelines for suspected cancer should be reviewed and acted upon as appropriate.
- Thought should be given as to how best communicate the updated NICE guidelines to GPs and tools should be developed/added to help implement them.

2. Allow GPs greater access to diagnostics

GPs need easy access to the right diagnostic tests to allow cancer to be diagnosed earlier or excluded from possible diagnoses. *Improving Outcomes: A Strategy for Cancer* committed £450 million to allow direct access to key diagnostic tests,⁵ however we know that there is variation in access across the country and it is not clear where the money has gone, or what its impact has been.

- New evidence for use of diagnostic tests in primary care settings should be reviewed, including the overall impact these may have on the diagnostic interval⁶ and outcomes;

⁵ Chest x-ray, non-obstetric ultrasound, flexible sigmoidoscopy/colonoscopy and MRI.

⁶ The first consultation with healthcare professional to diagnosis <http://www.ncbi.nlm.nih.gov/pubmed/22415239>

- Steps should be taken to address variation in adoption of the GP direct to diagnostics policy.
- Any funding commitments should be monitored and evaluated to ensure money goes where it is intended and results in earlier diagnosis.
- Any barriers to GP referral should be assessed and addressed (CR-UK is currently conducting research into this); including perverse incentives or tariff considerations which discourage GP direct access to diagnostic tests and/or onward referral for investigation where cancer is suspected.

3. Support the Health System to diagnose cancer earlier

- It is vital that diagnostic capacity issues are addressed as a matter of urgency. Recent evidence has shown that thousands of patients are waiting too long to receive results of their diagnostic tests.⁸¹ NHS England should review England's diagnostics equipment (including age and number) and workforce capacity (including related services such as pathology), in relation to other countries to ensure adequate investment and timely investigation and reporting of results. Cancer Research UK is currently undertaking work to understand the need in this area, and will input the findings gathered in due course.
- Best practice pathways which streamline and optimise the diagnosis pathway, including those being explored as part of the ACE programme, but also other innovative developments, should be evaluated and disseminated when evidence shows their benefit.
- NHS England should establish mechanisms to encourage CCGs to commission high quality diagnostic services, including requirements around reporting.
- We know that 'system delay' impacts the overall time to diagnosis.⁸² A better interface between primary and secondary care is needed to ensure patients move through the health system swiftly and smoothly. Further work is needed to break down barriers between these healthcare settings.

Improving access to cancer treatments

Cancer Research UK (CR-UK) would like to see a commitment in the cancer strategy to:

Substantially reduce variation in access to all effective cancer treatments, and to ensure all patients receive the best, evidence-based treatments available for their condition.

Overview

To improve cancer survival it is crucial that the NHS provides all cancer patients with the best treatment for their specific condition. Continued increases in demand for NHS cancer services and improvements in early diagnosis will mean more patients will require access to treatments that will provide them with the best outcome, with timely access to more curative forms of treatment like surgery and radiotherapy becoming ever more important.

As stated in the 5YFV, ‘it is not enough to improve the rates of diagnosis unless we also tackle the current variation in treatment and outcomes’. We know that variation in access to the best cancer treatments continues to exist. Addressing this must be a key part of the strategy.

Multi-disciplinary teams (MDTs) 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 and improving outcomes. However, recent research has shown that they are under growing pressure from increased demand and insufficient support, and are not operating as effectively as they could be.⁸³ It is vital that the cancer strategy sets out ways to support MDTs to work well for cancer patients, including looking at innovative methods such as virtual MDTs.

Most cancer patients will need a combination of surgery, radiotherapy and chemotherapy. Substantial improvements in access to all of these treatment modalities are required. Through research, cancer treatments are becoming increasingly targeted and the pipeline of these newer more precise interventions is strong. It is vital that the NHS is in a position to adopt evidence-based innovations that improve patient outcomes - including technology, medical devices, imaging advancements and drugs - as quickly as possible in a manner which ensures consistent access across the country. Further information can be seen in **Appendix B**.

Surgery

For many cancer patients, surgery offers the greatest potential for cure and is estimated to contribute to 5 in 10 cancer cures. The availability of improved techniques combined with projected improvements in early diagnosis means that more patients are likely to undergo surgery in the next 5 years. However, significant variation still exists in access to certain types of cancer surgery – addressing this would have a beneficial impact on cancer outcomes.

For some types of complex surgery there is growing evidence that centralisation will improve outcomes. However, this is not the case for all cancer surgery. Evidence on volume and outcomes must be taken into account as it emerges to determine future service configurations. Key aspects we would like to see reflected in the strategy are:

1. The NHS must reduce the variation in access to cancer surgery, particularly in older people

Variation in access to cancer surgery exists across England. For example, evidence shows geographical variation in access to lung resection⁸⁴, and while the overall lung cancer resection rate has increased⁸⁵, the proportion of patients having surgery remains low⁸⁶. In addition, recent data show that older patients are significantly less likely to receive surgery for their cancer than younger patients – this appears to be a problem for many types of cancer but is particularly acute for breast, kidney and ovarian cancers.⁸⁷ While many factors might be at play - frailty, suffering more than one illness,

being diagnosed at a late stage, patients choosing not to undergo surgery – these data paint a worrying picture.

CR-UK would like to see steps taken to reduce variation in surgical resection rates and a guarantee that patients are being given all they need to make an informed decision.

- Further work is needed to understand best practice in terms of access to surgery and any indefensible variation.
- More support is needed in hospitals to treat older people as surgical procedures, and recovery pathways, can be more complex due to factors such as co-morbidity.
- Dedicated resource will be needed to further investigate the reasons behind this variation and provide appropriate solutions. For example, solutions could include better use of comprehensive geriatric risk assessment⁸⁸, and some research has suggested that surgical representation at an MDT increases the chance of a patient receiving surgery.⁸⁹

2. Surgical innovations

The NHS must support research and innovation in cancer surgery. Past experience with evidence-based procedures such as Total Mesorectal Excision (TME), a technique developed in the UK but only rolled out across the NHS a decade later than in other European countries⁹⁰, suggests that there is a lack of clarity around how surgical innovation is disseminated in the NHS. The rollout of laparoscopic surgery, in contrast, succeeded as a result of the LAPCO national training programme.⁹¹

Current efforts within the cancer research community to increase surgical research activity should be supported⁹² and are likely to produce innovative techniques and technologies in the coming years. Advances in imaging and histopathology techniques will enhance our ability to select the patients that will benefit from surgery the most, and avoid surgery where it may not be appropriate. In addition, innovations in surgical techniques that are minimally invasive, and the development of intra-operative diagnostics to determine clearer margins, could substantially improve outcomes.

- NHS England in partnership with the surgical royal colleges and research community should develop clearer mechanisms to roll out any new surgical innovation as it is developed.
- The NHS must horizon-scan and consider evidence for innovative minimally invasive techniques (including robotic and navigated surgery) and intra-operative diagnostics to increase clear margins, for example, and develop strategies for their roll out in an equitable way.

3. Develop a comprehensive set of quality indicators for cancer surgery

Improving the quality of surgery is vital to improving cancer outcomes. Greater transparency and access to information about surgical performance drives improvements in the service, and there is a need to produce valid quality measures of surgery in the NHS. Surgeon-level outcomes data currently exist. However, while this is a positive step, there are concerns that these are a blunt measure which may make surgeons more risk averse. These indicators also do not appropriately reflect the complexity of surgery nor clearly show where good surgical practice is and is not happening⁹³. CR-UK would like to see NHS England work with the National Cancer Intelligence Network, professional bodies, patient groups and others to develop a comprehensive set of quality indicators for cancer surgery services. This will further our understanding of cancer surgery performance and incentivise greater improvements.

In addition, the quality of data on curative surgery should be improved as it is inconsistent. Whilst some is collected through the four national audits (lung, bowel, breast, head and neck), data on additional tumour sites is required, as is commensurate data on the demographic profile of those receiving surgery, as well as data on decision to treat and patient choice.

Radiotherapy

Radiotherapy can cure cancer, is cutting-edge and is cost effective.⁹⁴ 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.⁹⁵ However, access to radiotherapy continues to remain below levels recommended and varies across the country. The radiotherapy service will need a planned programme of investment and support over the next five years to modernise radiotherapy in England and ensure that all patients have access to the best, evidence-based treatment for their condition. This includes increased access to advanced forms of radiotherapy such as Intensity Modulated Radiotherapy (IMRT), Image Guided Radiotherapy (IGRT), Stereotactic Ablative Radiotherapy (SABR) and other forms.

Radiotherapy has become significantly more sophisticated over the past decade. Over the next 5 years research will bring even more ways to refine and develop new techniques that will be beneficial for patients. We would like to see the new cancer strategy build upon the shared aspirations set out in the Vision for Radiotherapy 2014-24⁹⁶, so that NHS radiotherapy services are equipped to provide more patients with substantially improved outcomes, higher cure rates, and fewer side effects from their treatment. Key aspects we would like to see reflected in the strategy are:

1. NHS England must ensure that all equipment, including linear accelerators (Linacs), is of high quality and capable of delivering advanced radiotherapy.

Urgent action is needed to replace outdated machines. The 2013 radiotherapy equipment survey showed that 101 Linacs are 8 years older or more, including 56 that are 10 years old or more⁹⁷. It is recommended that Linacs are replaced when over 10 years old⁹⁸. While it is the responsibility of NHS Trusts to replace equipment, this clearly is not working well and support at the national level is needed in the short term.

- A sustained programme of investment should be created to bring radiotherapy equipment up to date and to the minimum specification, including a dedicated Linac replacement scheme. If a new Linac costs on average £1.5million, we estimate that at least £150m will be needed over the coming 2-3 years to ensure all equipment is up to date.
- NHS England must ensure this situation does not arise in future and should develop innovative funding models which provide Trusts with a long-term and sustainable solution to updating equipment to keep pace with the latest technologies.

2. Variation in access to radiotherapy must be substantially reduced, particularly to advanced forms, and innovative evidence-based techniques must be quickly adopted.

Variation in access to radiotherapy continues to exist and it is acknowledged that uptake to innovative techniques in the NHS has been slow and inconsistent.⁹⁹ The last data we have seen showed that 38 per cent of cancer patients are accessing radiotherapy, when around 50 per cent should.¹⁰⁰ Access to IMRT still varies from 21 per cent to over 50 per cent across England, with 4 centres still not consistently hitting the 24 per cent standard.¹⁰¹ Further improvements are clearly needed - recent research has indicated that over 50 per cent of radiotherapy patients (on average across England) should receive IMRT.¹⁰²

The new strategy should make the case for a 'transformation fund' to ensure all patients get the treatment they need, including:

- Around 50 per cent of cancer patients having access to radiotherapy.
- At least 50 per cent of radiotherapy patients (on average) receiving IMRT.
- All radiotherapy patients receiving IGRT as appropriate for their treatment.
- Equal access to new, evidence-based technologies including SABR, proton beam therapy, and image guided RT and brachytherapy.

NHS England must plan for the consistent adoption of new technologies following clinical trial evidence and/or formal evaluation. We welcome the £15m over the next three years to support building the evidence base for innovative radiotherapy techniques; however, a long term approach to ensuring new innovations in radiotherapy are evaluated and rolled out effectively is needed. It will be important to maintain support for building evidence in new technologies – through clinical trials and other evaluation mechanisms - that could have positive impact on patient outcomes, for example the forthcoming MRI-Linac (estimated to come on stream by 2017/18). In addition, research into better combinations of therapies, such as using drugs as radio-sensitisers and therefore making radiotherapy more effective, may have a significant impact on outcomes.

3. Harness the power of data to understand radiotherapy service performance and improve clinical outcomes.

The Radiotherapy Dataset (RTDS) requires further work to make basic data regarding numbers of patients receiving treatment (and especially IMRT) available. This is long overdue and progress is required as a matter of urgency. NHS England should work with PHE to ensure the RTDS provides up to date, high quality data to inform commissioning and service development, including streamlining patient pathways.

A future aim should be to enable the use of real-time data to inform treatment options and predict patient outcomes. Radiotherapy data should be linked with the Cancer Outcomes and Services Dataset (COSD) and other datasets that may provide greater insight, such as the Systemic Anti-Cancer Treatment (SACT) dataset.

Chemotherapy and cancer drugs

Chemotherapy and other drug treatment play a vital role in the treatment of cancer. They are estimated to contribute to 1 in 10 cancer cures in their own right, but also play a crucial role in combination with other treatment modalities.

We are now in an era where medicines are able to target genetic mutations (and other biomarkers) in a patient's cancer and enable a patient's immune system to attack tumours. More drugs like this are in development and will become available over the next 5 years. With targeted medicines in particular we must acknowledge issues around resistance, but there is no doubt that these medicines are the future of cancer drug treatment.

However, in England, there remains a fragmented and inflexible policy environment for the funding of cancer drugs – this must be addressed for the long-term. In addition, mechanisms should be established to ensure equal access to cancer drugs once available on the NHS. Key aspects we would like to see reflected in the strategy are:

1. The development of a long term, comprehensive solution to funding of cancer drugs

- The NICE drug appraisal process should be reformed to account for the advancements that have been made in cancer medicines. We would like to see it become more flexible than a system that offers rigid 'yes' or 'no' judgements. Such reforms should seek to ensure that additional funding schemes such as the Cancer Drugs Fund (CDF) are not needed, so that we can move towards having one mechanism for cost-effectiveness judgements and routine funding decisions in England.
- A review of access to cancer drugs across the country should be undertaken, setting benchmarks for access based on incidence in different areas and comparing this with prescribing data as well as data from the SACT dataset. This review should also demonstrate the impact of drugs accessed through the CDF.

- NICE should consider using or supporting formal evaluative mechanisms such as conditional access mechanisms to determine effectiveness of drugs where clinical trials are not appropriate – for example for rarer cancers and smaller populations. However, appropriate standards of evidence must be agreed ahead of any initiative and in consultation with the research community.
- NHS England's Individual Funding Request (IFR) system must become more flexible, ensuring that clinicians are able to support some patients in very difficult clinical circumstances to access treatments that are not routinely funded. Currently only a very small number of patients receive treatment via IFRs and the decision making process is not transparent.
- The Department of Health should monitor lessons arising from the adaptive pathways pilots led by the EMA around approaches to reimbursement early in the process, despite data uncertainty.

2. An NHS that ensures all patients receive the best medicines for their condition

Once a cancer medicine is available on the NHS, it is crucial that mechanisms are in place to ensure the right patients access them. We want to see the Government and NHS England realise their commitment to implementing a nationally-commissioned molecular diagnostic testing service to ensure all cancer patients have access to the best, evidence-based treatment for their condition. This commitment was made in the 2011 cancer strategy,¹⁰³ but it is yet to be fulfilled. National variation in access to these tests and in funding mechanisms remains, meaning some patients are not getting the drugs that could help them the most.

The establishment of this service would help future-proof the NHS for when further personalised medicines come on stream, potentially arising from research based on the 100k genomes project. It could also facilitate recruitment to trials by identifying eligible patients. In the future, the use of panel testing will enable further efficiency by driving forwards economies of scale, and patient benefits by identifying a wider range of molecular targets that may be present within their cancer.

3. Better chemotherapy data and informatics

Robust chemotherapy data has the potential to transform our understanding of the impact of cancer drugs on patient outcomes. It can also inform commissioning decisions. We are encouraged by the development of the Systemic Anti-Cancer Therapy (SACT) dataset. However, data collection and publication on chemotherapy activity, outcomes and costs was scheduled for delivery in April 2012. While some progress has been made, especially recently, this is still not routinely available at provider or CCG level and no clear plan for what data will be made publicly available and when has been put in place. More work is clearly needed to increase data quality and the proper resources are needed to support its further development.

The SACT should become a high quality dataset, which allows for a truly evaluative 'real world' data system within the NHS. It is vital that hospitals are supported to provide robust data so that this can become a reality. This is particularly important for mechanisms such as conditional access mechanisms, where robust data on the effectiveness of treatments is vital to understand their impact, particularly where trial data is insufficient (e.g. in drugs used for rarer cancers).

Realising the power of this data over the next 5 years – by improving data quality and linking with other key datasets - should be a key part of the new strategy.

Barriers to improving cancer outcomes

We want cancer outcomes in the UK to be the best in the world. To do this we need well resourced and functioning NHS cancer services. However, significant barriers need to be overcome to really provide a world-class service that patients need. CR-UK published a report in 2014 analysing the state of cancer services in the NHS in England¹⁰⁴. This research highlighted some key areas that must be addressed to ensure our NHS becomes the best in the world.

1. Greater investment in NHS cancer services is required

Analysis of NHS England Programme Budgeting data found that real terms spending on cancer has essentially remained flat since 2009-10. This, coupled with a huge increase in demand for cancer services, means that cancer services are starting to struggle. This has been indicated through the 62 day wait standard - between urgent referral and first treatment – being missed for the last four quarters. Demand for services is beginning to outstrip supply and further investment is now necessary.

“We need more funding. Instead of progressing/developing our cancer services which are already significantly underfunded, our services are actually being cut. It is becoming impossible to deliver all the new cancer targets and quality of care is deteriorating.” – Allied Health Professional

- Spending on cancer and tumours peaked in 2009-10 at £5.9 billion in England. In the two following years to 2011-12 there was a real term decrease of 6 per cent, before a slight increase to reach £5.7 billion in 2012-13
- In 2013-14, over 1.4 million patients in England were referred by their GP for suspected cancer - a 50 per cent increase in referrals from 2009-10.

CR-UK has commissioned some work to try and quantify what is needed to deliver world-class cancer services and will input any information gathered in due course.

2. There is a vital need for better leadership in cancer

Our research has found that the reorganisation of the NHS has led to a ‘vacuum’ of leadership at the national level needed to drive forward the cancer agenda. A lack of basic support and resources for leading strategic developments was also raised as a key issue at local level – the disbanding of cancer networks into strategic clinical networks (SCNs) seen as a particular problem.

We welcome the commitment from NHS England to build on current resource and add further capacity in cancer policy to drive forward improvements. However, better leadership and coordination across all health bodies is needed. A recognised cancer leadership team that coordinates work and provides strategic oversight to NHS England, Public Health England and the Department of Health, would build on current additions and provide a truly coherent approach to cancer leadership in England.

3. Clarity of cancer commissioning responsibilities

The roles and responsibilities of the new NHS organisations are generally not well understood, leading to concerns about fragmentation in commissioning along the cancer patient pathway. Local authorities are responsible for public health, along with Public Health England; Clinical Commissioning Groups are responsible for commissioning services for the more common cancers, including diagnostics services; NHS England commissions specialised services including radiotherapy and chemotherapy. All this has led to confusion around who commissions certain services and urgent clarification of this is needed.

In addition, significant concerns have been raised about the reconfiguration of cancer networks into strategic clinical networks (SCNs), with the cancer community saying that the loss of cancer networks has had a detrimental impact on the provision and quality of care¹⁰⁵. While SCNs do have a remit to improve cancer care, it is clear that network resource dedicated to cancer has been diluted. Serious consideration should be given to the effectiveness of SCNs in the role to improve cancer care across England, and actions be taken to ensure they are resourced help improve cancer services.

4. Workforce

Workforce issues are a major barrier to achieving world-class cancer services. A long term strategy is needed to address shortages in number of staff, as well as providing staff with the required expertise to provide the best care.

Recent research by the Royal College of Radiologists has highlighted the chronic shortages of radiologists¹⁰⁶, leading to a backlog in reporting of diagnostic tests, which could delay life saving treatment. Shortages in staff numbers is also seen in the radiotherapy workforce – with a lack of medical physicists and radiographers in particular¹⁰⁷ – as well as lack of training to deliver advanced radiotherapy techniques, providing challenges to delivering the best treatments to patients.

5. Payment mechanisms

The strategy must look at how services are paid for and how this incentivises best practice. We are aware of perverse financial incentives within the NHS that encourage the delivery of suboptimal care and disincentivise uptake of innovative, evidence-based practice, for example:

- In diagnosing colorectal cancer, the tariff currently incentivises a consultant-led face-to-face appointment over a nurse led telephone consultation when the latter is widely regarded to be the more innovative pathway and can save money.
- Research into new radiotherapy techniques is showing that fewer, high dose, fractions (termed hypofractionation) is as effective as current treatments, meaning fewer trips to hospital for patients. Yet payments per fraction, as currently set up, disincentivise centres from adopting evidence based practice. It has taken a mandated QIPP⁷ target from NHS England to increase adoption of best practice of 15 fractions to treat breast cancer (based on evidence from START trials¹⁰⁸) as opposed to 25 fractions. It is estimated that if 90 per cent of breast patients are treated with 15 fractions, this would save the NHS nearly £2.5m.

⁷ Quality, Innovation, Productivity and Prevention programme

Research

Research continues to be pivotal to developing our understanding of preventing, managing and curing cancer. It is at the heart of our progress in doubling cancer survival over the past 40 years. Underlying progress in all key areas for our stated commitments is an active and vibrant research culture in the NHS.

The 5YFV is unequivocal in its support for the progress that can be achieved through research: *“Research is vital in providing the evidence we need to transform services and improve outcomes. We will continue to support the work of the National Institute for Health Research (NIHR) and the network of specialist clinical research facilities in the NHS.”*

Government’s continued support for the clinical research environment is crucial and we wish to see it maintained and strengthened to support cancer research. Participation in research has dramatically increased since 2001, largely due to the formation of the National Cancer Research Network (NCRN) in 2001 and the National Institute for Health Research (NIHR) in 2006. The UK is now world-leading in the number of cancer patients that participate in research: nearly 57,000 in 2012, 1 in 5 of all UK cancer patients¹⁰⁹. Key aspects that we would like to see reflected in the strategy are below. Further information can be seen in **Appendix C**.

Supporting clinical research in the NHS

While gains continue to be made it is vital that the NHS as a whole makes research a core function of everyday care so that progress can continue to be made in the prevention, diagnosis, treatment and management of cancer. Research by the University of Birmingham for CR-UK (to be published shortly) provides further evidence that a strategic approach to research is needed to ensure that all elements of the health service supports research.

“There is a significant degree of variation in how research is managed and undertaken within the NHS, with examples of highly motivated and highly research-active ‘pockets’ of clinicians within organisations, as well as organisations that have a broader coverage of research activity across teams and departments. Further growth and subsequent sustainability in research terms is likely, however, to require an approach where research activity is more distributed at all levels i.e. more individuals, more departments and more organisations are involved in undertaking research but under the guidance of strong leadership.”

To support NHS England’s overall vision of a research active workforce we strongly recommend that a research strategy including all major partners is developed to ensure that all levels of the health service are clear about what needs to be achieved.

In addition to this, we would like to see:

- 1. Commitment for the NHS to meeting the Excess Treatment Costs (ETCs) of all forms of cancer trials running in the NHS, in accordance with the Health Service Guidance agreement, Health and Social Care Act 2012, the NHS Mandate, NHS Constitution and AcoRD guidance.**

ETCs are a critical component of clinical research, without them non-commercial funders would not be able to support the full cost of running a trial resulting in a significant decline in the number of trials running in the UK. ETCs are therefore vital to clinical research directly leading to new and better treatments to improve the health of UK patients.

As well as providing the foundations for a research active NHS, ETCs can also leverage significant amounts of investment. Since 2008, CR-UK trials have secured the support of over 50 pharmaceutical

companies which provided £300m of support for access to free drugs and educational grants for patients whose treatment would otherwise have been paid for by NHS budgets.

Commissioners should encourage NHS Trusts to take part in as much research as possible, and should accept that there will be a mix of studies where ETCs offer either savings or costs to the service. Studies must be taken 'in the round' and not scrutinised on an individual case by case basis. By accepting a mix of studies commissioners will ensure that all forms of research have the opportunity to take place across the whole NHS.

As part of the cancer research community's plans to expand the amount of clinical research taking place in the UK there needs to be support for ETCs by commissioners and senior staff across the health system. Greater amounts of cancer research will be conducted into behaviour, prevention and early diagnosis therefore it is important to ensure that commissioners for primary care services understand the rationale for meeting ETCs.

2. The NHS fosters a supportive culture for research and collaborates with Government and regulators to improve the running of research in the health system. In particular working with the NIHR to deliver research projects across the research network and the HRA to streamline regulatory and governance approvals.

In order to fully exploit the world-class clinical research expertise and infrastructure in the UK there needs to be a supportive regulatory environment. Governance continues to be the primary barrier to conducting research in the NHS. A single trial can take place across multiple trusts so obtaining governance approvals from each participating Trust, which may have different approval criteria and often duplicate checks, can cause significant delays. Delays in site approval limits patients' access to research studies and delays the whole research process meaning investment in research takes longer to adopt into clinical practice.

Work across the NIHR and the recent formation of the Health Research Authority (HRA) has supported the improvement of the governance processes. The HRA has been tasked to deliver a single assessment process (known as HRA Approval) for all clinical studies by the end of 2015. CR-UK is supportive of the HRA's work to streamline the approval and set up of research in the NHS and is piloting several schemes through the ECMC network. It is important that the HRA continues to receive support for its work to harmonise and streamline the regulation of research in the NHS. To achieve this NHS Trusts and their R&D departments need to work in collaboration with the HRA to ensure that the elements of the single assessment are recognised and adhered to at a local level.

Data and patient information

CR-UK believes that data accessibility, and the systems, governance and people which ensure its quality (referred herein as ‘informatics’) need better and more coordinated support at senior levels if outstanding commitments made in the 2007 and 2011 cancer strategies are to be met and then built upon. Particularly, gaps in data at specific parts of the cancer pathway need to be addressed to ensure evidence based improvement and innovation going forward; and progress on commitments regarding the sharing of health system data publicly, as outlined in the government’s transparency agenda, need to be reviewed to ensure work is progressing as expected.

The 2011 cancer strategy noted that, to be effective, information must be informing (comprehensive and trusted), engaging and empowering and, in line with the transparency agenda, available to the public. To meet these long-stated commitments we would like to see following three broad areas receive refreshed focus in the cancer strategy:

1. Drive up overall data quality through improved and sustainably resourced informatics, including sufficient capacity to analyse and interpret data to inform commissioning of cancer services.

While improvements in the systemic collection of cancer data have been made over the last five years, with the modernisation of the National Cancer Registration Service (NCRS) and the development of the Cancer Outcomes and Services Dataset (COSD), the focus is still primarily on provider compliance of the minimum dataset. Further work is needed to ensure the full breadth of indicators within the COSD are collected, with a revised and pragmatic timetable for implementation created, and greater efforts are made to increase access to data to inform commissioning of cancer services. Specifically, emphasis must be placed on resources, systems and support available at provider level.

- Initiatives such as the National Data Improvement team should continue to be resourced and expanded to compliance of datasets on which the COSD relies (e.g. SACT, RTDS).
- The NHS IT infrastructure needs to be designed to seamlessly deliver information, in a standardised way, from health professionals and providers to repositories such as NCRS and HSCIC and back again. Sending data to registries should not be seen as a one directional activity. Data flows should foster dialogue between providers, health professionals and the systems and people who receive data.
- Information flows should be future-proofed against possible restructures across the healthcare system. As models of care become more integrated, relevant data must be accessible to all bodies responsible for individual and population level health and wellbeing. Particularly, linked public health and hospital (HES) data must be accessible to both the NHS and relevant public health bodies, such as PHE and, if appropriate, Local Authorities.

2. Improve data transparency and public access

As a system of universal healthcare, the NHS comprises a uniquely rich resource to inform both practice and the research which drives its improvement. However, the interpretation of Information Governance protocols and public perception about data sharing has been significantly damaged since the poor communications around care.data. The way in which patient data are collected and used should be more obvious to cancer patients. CR-UK has worked with the NCRS and with cancer patients to develop a new Patient Information Leaflet to inform patients about the registration process. We are also working with the NCRS and the Braintrust to provide patients with access to their own cancer registration records. Greater attention and resources should be given to work that builds patients' knowledge of and support for these important initiatives.

There is a need to better define the debate around transparency and specifically to separate out the sharing of high quality trust/population level data and of patient identifiable data, to ensure the former is not held up by understandable concerns regarding the latter.

- Clarity around what level of COSD data will be available for third parties is required. We would like to see all provider/population level data where cases are greater than 5 are made available, in line with current Information Governance protocols.
- The National Cancer Intelligence Network (NCIN) should be suitably and sustainably resourced to support commissioners, inform providers and ensure high quality analysis and interpretation of raw data is available publicly.
- A follow up review of “Liberating the NHS: An Information Revolution” in the context of cancer data specifically, and broadening its remit from patient data to commissioners and providers, would go a long way to ensuring that cancer specific data is on track to meet revised expectations around health data set out in the Prime Minister’s letter to the Cabinet in July 2011¹¹⁰.

3. Improve data on screening, treatments and patient experience.

We would like to see the cancer strategy address the following gaps in data collection at specific points of the cancer pathway:

- **Screening:** The bowel screening annual report should include data on bowel scope, FOBt and FIT (when it comes online) coverage and uptake, eventually linked to system and outcome indicators;
- **Diagnostics:** Improvements should be made in the collection of data on GP usage of diagnostic tests, as mentioned in 2011 strategy, but not enough progress has been made. Having this data will allow GPs to benchmark their performance in relation to the diagnosis of cancer;
- **Treatments:** See section on access to treatments for further details (Pages 11-15). For all treatment, locally aggregated data to identify and understand **inequalities**, across geography and socio-economic factors is required. A commitment to help improve intervention rates in the **older population**, through routine collection of data on rates and regional variations, made available to commissioners, providers, the public and patients was made 2011. More progress is required here in particular; and
- Standardised collection of cancer **patient experience in young people** is recommended. The National Cancer Patient Experience Survey (NCPES) starts with those aged 18 and over. Evidence suggests teenage cancer patients have unique needs¹¹¹, for example regarding psychological support, and these need to be better understood if they are to be addressed.

The importance of good quality information for patients

The strategy must address the information needs of patients. Patients must have access to and be given good quality information about their condition and treatments they may receive. Information helps patients feel more in control of their situation, is essential for informed consent and in decision making.

- Although provision of information for cancer patients in the clinical setting has improved, almost 30 per cent of patients state that they were not given written information about their cancer and there are still distinct variations in different cancer types.¹¹²
- Patients also report preferring information broken down by what is relevant at different points on the cancer journey. CR-UK and Macmillan Cancer Support worked with NHS Choices to pilot information prescriptions to address this need.¹¹³ It is important that the learning from this project is not lost, and that individualised patient information resources continue to be developed and introduced into practice. As a greater range of treatments specific to the individual cancer patient are developed, it is likely that the need for

individualised patient information will grow and generic information packs become less relevant.

APPENDIX A – Cancer prevention

Further information and evidence:

- NHS England's Five Year Forward View states that *'England is too diverse for a 'one size fits all' care model... But nor is the answer simply to let 'a thousand flowers bloom'.*¹¹⁴ This summarises the opportunities and challenges faced by local authorities tasked with managing local public health service provision. There is also uncertainty about long-term funding.
- The social determinants of health (SDH), commonly termed the 'causes of the causes', are an increasing school of thought in the public health arena, and which contextualises many of the problems of health inequality. The World Health Organisation's (WHO's) *Action: SDH 'All for equity'*¹¹⁵ programme highlights the increased focus on this area as a global challenge. Public Health England's local *health profiles* project¹¹⁶ is an example of a resource which can contribute to the identification of, and action on the range of issues which influence the variation in life expectancy across England.

Tobacco control

- The cumulative efficacy of comprehensive tobacco control measures in driving down smoking rates across the UK is manifest in the prevalence trend which has accompanied the restrictions on tobacco sales, marketing, promotion and exposure since the 1960s and 70s.¹¹⁷
- The emergence of electronic cigarettes (e-cigarettes) creates new opportunities for strategies to tackle both tobacco use and nicotine dependence but there are challenges which need to be addressed including the growing involvement of the tobacco industry in the e-cigarette market.
- Exploring the major questions which form the e-cigarette debate is a key challenge for the entire public health community. Significant and sustained investment will be necessary to provide answers regarding the safety, efficacy and long-term impact of these new products. Recognising this challenge, CR-UK has committed £5 million over the next five-years to research into the health effects of e-cigarette use.

All political and public health stakeholders should share in an ambition and a vision toward a tobacco-free UK (with less than 5 per cent adult smoking prevalence)

- In 2014, agreement was reached by member states on a revision of the EU Tobacco Products Directive (2014/40/EU) (TPD). Having entered into force on 19 May 2014, the TPD will mandate a number of new changes such as increased packs health warnings, a ban on flavourings and on novelty pack shapes and openings. The TPD will, for the first time, introduce regulations on e-cigarettes on the basis on their being a licensed medicinal product or sold without a license as a consumer product.
- The WHO Framework Convention on Tobacco Control (FCTC) was the first treaty negotiated under the auspices the WHO¹¹⁸ and was developed in response to the globalization of the tobacco epidemic. In 2012 The Protocol to Eliminate Illicit Trade in Tobacco Products was adopted by the Parties, demonstrating how the FCTC continues to be a standard bearer for international standards.

Address smoking related health inequalities

- Smoking is a greater cause of health inequality than social position, underlining that without reducing smoking prevalence in the most deprived groups (as well as reducing the number of smokers overall), policies designed to reduce health inequalities will have limited success.¹¹⁹
- Raising tobacco taxes is one of the most effective ways of reducing tobacco consumption, something the tobacco industry itself admits.¹²⁰ There is strong evidence that increase in the price of tobacco products have a pro-equity effect on smoking behaviour in adults.^{121, 122} A similar observation has been made in regard to interventions to create progressive equity impact among young people,¹²³
- Tobacco industry pricing strategies undermine policies to reduce health inequalities. In recent years 'Ultra Low Price' (ULP) cigarette brands have proliferated in the UK market.¹²⁴ Examining the real

price of individual ULP brands shows that some have fallen by as much as 5 per cent¹²⁵ giving smokers access to cheaper tobacco. Research shows that between 2006 and 2009 the ULP market doubled.¹²⁶ There has been an increase in the sales volumes of economy brand cigarettes and the use of hand rolling tobacco which is undermining efforts to reduce smoking rates.¹²⁷

- Individual level smoking cessation interventions, unless specifically targeted to address inequalities, are at risk of widening health inequalities. NHS stop smoking services are successful at preferentially enrolling those of lower socio-economic status providing balance for the fact that success rates for quit attempts are lower in these groups.¹²⁸ Given that behavioural support and prescription medication from the NHS stop smoking services offer the best possible chance of smoking cessation, it is of concern that popularity has decreased over the previous two years¹²⁹, with the rise in the popularity of e-cigarettes.
- Tobacco-use patterns in different minority groups should also be considered, for example more needs to be done to address smoking rates in the prison population where it is estimated 80 per cent of inmates smoke, which can be partly attributed to prevalent mental health issues within amongst the prison population.¹³⁰

Comprehensive tobacco control policies and investment at national and local level

- The Smokefree Action Coalition (SFAC) has promoted the NHS Statement of Support on Tobacco Control and Local Government Declaration¹³¹, to which local authority representatives, responsible for commissioning services can affirm their support for tobacco control, in line with NICE guidance, delivered through community health services, acute trusts, local authorities and wider community partners. Positive commitments from local authorities much be backed up by investment needed.
- A quit smoking attempt with NHS stop smoking services is around three times likelier to be successful than attempting to stop unassisted.^{132, 133} Around half of NHS stop smoking services users in England in 2010/11 were in receipt of free prescriptions (an indicator of relative disadvantage).¹³⁴
- Unpublished analysis shows that local authority's tobacco control budgets have so far held up fairly well since transition, but this needs to be monitored ahead of expected cuts. The report found that tobacco control or smoking cessation budgets had been cut in 7 per cent of local authorities due to cuts in supposedly ring-fenced public health budgets. While this is only a minority of incidence, the author notes, *'...if public health budgets can be cut when they are protected by a ring-fence, there is clearly a risk that many more budgets may suffer when this ring-fence is removed'*.¹³⁵
- In December 2014 HM Treasury launched a consultation on the potential design for a levy of tobacco manufacturers and importers¹³⁶ as was announced in the Autumn Statement 2014.¹³⁷ The tobacco industry should be accountable for the negative externality they create and a levy of tobacco manufacturers based on market share (clearances) provides a mechanism to source new funding for stop smoking services, mass media campaigns and efforts to tackle the illicit trade.

Alcohol

- In 2012 among adults who had drunk alcohol, 55 per cent of men and 53 per cent of women drank more than the recommended daily limits (2-3 units and 3-4 units respectively) in England, including 31 per cent of men and 24 per cent of women who drank more than twice the recommended limits.¹³⁸ In addition, almost a quarter of men (24 per cent) and a fifth of women (18 per cent) drank more than the recommended weekly limits (21 units and 14 units respectively) in 2012.
- There is a relationship between alcohol related mortality and socioeconomic status in England and Wales with progressively higher rates in more deprived areas.¹³⁹ It has also been found that tobacco and alcohol related cancers in the UK are 2-3 times more common in areas of the most deprivation than the least.¹⁴⁰ This is despite less deprived people, by various measures, being both more likely to drink alcohol, and likely to drink more of it, than more deprived people. The disproportionate burden of harms experienced by those of higher deprivation is termed the 'alcohol harm paradox'.

- Given that low levels of drinking can increase the risk of cancer, it is better to focus on population level measures to reduce total alcohol consumption amongst drinkers than target only harmful or dependent drinkers.
- A comprehensive approach to alcohol harm reduction should tackle the key drivers of harmful drinking – price, marketing and availability. Tackling marketing is necessary as research demonstrates that young people who are exposed to alcohol advertising have an increased likelihood of starting to drink alcohol and will drink more if they already do so.¹⁴¹ Price increases have also been shown to translate to both reduced consumption and reductions in alcohol-related harm.¹⁴² There is also evidence that when the availability of alcohol is restricted, consumption and its associated harms decrease.¹⁴³
- It is important to continue funding for mass media campaigns to increase awareness of the health harms of alcohol. In particular health campaigns should aim to increase awareness of the risks of chronic disease such as cancer and the contribution of alcohol to calorie intake. It is important that alcohol health campaigns are regularly evaluated to ensure they help reduce harmful drinking and not just raise awareness of the harms of drinking.

Obesity, diet and physical activity

- Unhealthy diets (such as those lacking in fibre, fruit and vegetables or high in processed meat, red meat or salt) have been independently linked to cancers of the bowel, stomach, mouth and oesophagus. Together these dietary factors are linked to almost 30,000 cases of cancer a year in the UK.¹
- The evidence suggests that obesity is more prevalent in the most deprived groups in the UK¹⁴⁴ and therefore requires strategies that can enable the most deprived groups in society to eat healthily, be more physically active and maintain a healthy weight in order to reduce inequalities. Children of lower socioeconomic status are more likely to be obese, with childhood obesity prevalence nearly double among the most deprived year 6 children compared with the least deprived year 6 children in 2012/13.¹⁴⁵
- If current trends in BMI continue unabated it is predicted there will be an increase of 87,000-130,000 cases of cancer in the UK between 2010 and 2030, whilst a 1 per cent reduction in BMI for every UK adult could avoid 32,000–33,000 cases of cancer over this period.¹⁴⁶
- The Foresight report demonstrated the complexity of factors that influence obesity.¹⁴⁷ But the approach to reducing obesity levels has been largely piecemeal and unsystematic.
- A recent report by McKinsey highlighted that Governments should not seek the “best” intervention but aim “to do as much as possible as soon as possible.” Reviewing 44 interventions for the UK the authors found that all proposed interventions were cost effective in reducing obesity and that implementing all of these at the population level could reduce obesity and overweight rates by 20 per cent and save over £16bn a year and almost £800m for the NHS.¹⁴⁸
- Among the drivers of unhealthy diet is the marketing of unhealthy “junk” food. This is of concern as the food marketing and advertising influences children’s food preferences, and encourages them to ask their parents to purchase foods they have seen advertised. It can also affect their consumption and other diet related behaviour.¹⁴⁹ Price has been identified as a factor that affects the purchasing of unhealthy food.¹⁵⁰ Measures to tackle the price of unhealthy food should be explored particularly where the impact is greatest on young people.
- The Government’s colour coded front of pack nutritional labelling scheme has been a popular with 81 per cent of the public using the labelling to aid purchase decisions.¹⁵¹ It is important that this scheme continues and is expanded to cover as wide a range of products as possible.
- There is much more to be done to encourage further physical activity across the population. Local measures to increase levels of activity are likely to have the greatest impact. In particular promoting more ‘active travel’ can help increase total physical activity.¹⁵²

Ultraviolet (UV) radiation

- In 2011, there were around 100,000 non-melanoma skin cancer cases registered in the UK, though the real number of cases is thought to be much higher.^{153 154 155 156} Over the last 30 years malignant melanoma incidence rates in Great Britain have increased more rapidly than any of the current ten most common cancers in men and women, however overall mortality rates have seen a much smaller increase over this time.^{ibid}
- England should look to the successful approach taken in Australia towards stabilising malignant melanoma rates. An effective skin cancer prevention strategy should include measures to reduce sun exposure in at-risk groups, mass media campaigns to increase awareness of the risks of sun exposure, understanding of when UV protection should be used and the best ways to protect skin, and to encourage safer behaviour, and further regulation of sunbeds.
- The evaluation of the Sunsmart campaign in Australia demonstrates that it both increased awareness of the harms of excessive sun exposure and helped change behaviour in terms of seeking shade, wearing appropriate clothing and using sunscreen.¹⁵⁷ It also showed that rates of malignant melanoma had begun to plateau after decades of increasing.^{ibid}
- In addition to mass media campaigns, further guidance and support is needed at the national and local level for groups likely to have higher UV exposure particularly outdoor workers and those at higher risk of skin cancers. Guidance should be provided to outdoor workers to ensure that adequate clothing and sunscreen is used as part of the normal routine to reduce the risk of skin cancer among those workers.
- Further regulation of sunbeds is necessary in England. The ban on under-18s using sunbeds has led to a decline in the proportion of young people using sunbeds. However 4.5 per cent of 11-17 year olds have used a sunbed.¹⁵⁸ This in part may be due to the fact that in England unsupervised sunbed use is still permitted.

Human Papilloma Virus (HPV) prevention

- Infections with various types of HPV can also lead to anal¹⁵⁹, penile¹⁶⁰ and some types of oral and oropharyngeal cancer¹⁶¹, as well as genital warts. Oral and oropharyngeal cancers are increasing in incidence in the UK¹⁶², and, over time, a higher proportion of cases are being linked to HPV infection.¹⁶³ The high coverage of HPV vaccination means that heterosexual men may benefit from herd protection. However men who have sex with men cannot benefit. This group already experiences high rates of HPV infection and HPV-related cancers, and this inequality will widen significantly over time unless action is taken.
- Vaccinating all boys is likely to be the best option in terms of improving health outcomes and reducing health inequalities. However, there is insufficient evidence currently to show whether this approach is cost effective.

APPENDIX B – Access to treatments

Multidisciplinary teams (MDTs)

- A report commissioned by CR-UK *An evaluation of cancer surgery services in the UK*:¹⁶⁴ recognised that MDTs represent a gold standard of cancer treatment. However, they are becoming increasingly stretched, with increasing caseloads and therefore less time to consider individual cases.
- The usual pattern reported was a weekly one-hour MDT considering eight to ten patients at each session, but some reported considering sixty patients over an hour and a half session.
- Delays in receiving information from other units (e.g. patient scans) were raised as a concern.
- Some specialties shoulder a larger burden in preparing for MDTs – it was estimated that radiologists might have to spend four hours preparing for an MDT.
- Some MDTs are using virtual MDTs (vMDTs), carried out through videoconferencing or other methods, to connect multiple sites and avoid travel costs.

The report recommended:

1. **Commitments to developing and supporting MDTs are needed within both local plans/programmes to develop cancer services.**
2. **There is much research and piloting work underway to support the development of telemedicine within the NHS; this could usefully extend its focus to include models of remote clinical team working such as virtual MDTs (vMDTs).**

Surgery

Quality and performance

- A report commissioned by CR-UK *An evaluation of cancer surgery services in the UK*:¹⁶⁵ found that surgeons across the UK were broadly supportive of moves towards greater transparency around performance measurement, which is being realised through the publication of surgeon-level mortality data for 10 surgical specialties. This supports transparency for patients and conversations around quality improvement.
- However there were concerns that transparency could lead to risk aversion, particularly amongst surgeons working in higher-risk specialties.
- Furthermore, concerns were expressed that mortality data at a surgeon level does not capture the complexity of surgery:
 - Surgery is a ‘team game’.
 - Short term survival data (e.g. 30 or 90-day mortality depending on the specialty) does not give a full picture of the quality of the surgery that was performed.
 - There will be different types of indicators that will be relevant depending on the type of surgery in question.

The report recommended:

1. **National health departments should work with the National Cancer Intelligence Network, professional bodies, patient groups and others to develop a comprehensive set of quality indicators for cancer surgery services.**
2. **NHS England should reconsider the inclusion of certain cancer specialties in its drive to report surgeon-level outcomes.**
3. **NHS policy makers should be required to routinely gather patient-reported outcomes, in order to assess the impact that surgical interventions (and other treatments) have on recovery outcomes and patients’ quality of life.**

Radiotherapy – Vision for Radiotherapy 2014-24

- Radiotherapy can cure cancer, is cutting-edge and is cost effective.¹⁶⁶ It is second only to surgery in its effectiveness in treating cancer, and experts suggest around four in ten patients whose cancer is cured receive radiotherapy.¹⁶⁷ Around 50 per cent of cancer patients should receive radiotherapy as part of their treatment.
- Radiotherapy has become significantly more sophisticated in the last decade. Advanced radiotherapy treatments target tumours more accurately and reduce the irradiation of healthy tissue, improving patient outcomes and reducing side effects. But while technical advances are being made, historically the NHS has not adopted innovations into clinical practice in a consistent and equitable way in radiotherapy centres across England. NHS England now commissions radiotherapy for the whole of England, offering a real opportunity to drive improvements consistently across the NHS.
- The Vision sets out NHS England's and Cancer Research UK's shared vision for the future of innovation in radiotherapy. A clear vision provides the NHS with a framework to build an effective strategy to meet the Prime Minister's commitment, that from April 2013 onwards, patients will be guaranteed access to innovative radiotherapy where clinically appropriate and cost-effective.

Our **vision** for patients requiring radiotherapy in the NHS in England is that:

All patients will receive advanced and innovative radiotherapy that has been shown to be clinically and cost effective. Radiotherapy will provide patients with substantially improved outcomes, higher cure rates, and fewer side effects from their treatment.

Innovation in radiotherapy will enable:

- Stratification of patients who will benefit from radiotherapy.
- Personalisation of radiotherapy treatment based on physical and biological characteristics of the patient and their disease.
- Treatment to be adapted to the patient during the course of treatment, reacting to physical and biological changes, for example, due to innovations in real time imaging and the use of biomarkers.

NHS England will need to ensure that all radiotherapy centres meet national standards through the application of robust service specifications and the quality dashboard. This will include the right equipment, workforce capacity and capability to deliver optimal, high quality treatment to all patients in a timely manner, wherever they live. This will require focus on the following key elements:

1. Strong leadership at national and local levels

Effective leadership in NHS England and radiotherapy centres is vital to meet the challenges to innovation in radiotherapy, and particularly in encouraging strong partnership working between centres. Robust commissioning levers and incentives at the national level will be necessary to drive innovation and efficiency in radiotherapy and remove outdated practice.

2. Standardised treatment protocols

A consistent approach to the treatment of patients with radiotherapy using nationally agreed protocols to ensure patients have the same standard of treatment regardless of where they live. Waiting times for treatment will be further reduced as appropriate for each type of cancer or condition to avoid unnecessary delays.

3. Evaluating and quickly adopting innovation

The timely formation of national clinical policies to support the rapid adoption of affordable new technologies, including treatment devices, imaging techniques and treatment planning software, across the NHS is needed, where evaluation has shown clinical effectiveness and cost effectiveness.

4. Realising the full potential of advances in treatment imaging

Some of the greatest foreseeable improvements in radiotherapy will be driven by advances in imaging, with advances being made across the radiotherapy pathway. Real-time, multi-modality imaging and the identification and validation of predictive biomarkers will drive personalisation of treatment, and the ability to assess patient responses during treatment.

5. Optimising the highly skilled workforce

Taking full advantage of advances and innovations in radiotherapy will require highly skilled staff, effective team working, training and sufficient capacity in the workforce. New models of working will be crucial to deliver advanced treatments and supportive care across radiotherapy pathways.

6. Harnessing the power of data

Data generated from radiotherapy planning and treatment, for example the Radiotherapy Dataset, has the potential to provide powerful insights into the delivery of radiotherapy. It can also inform research and innovation. Data must be used to its full potential, including linking with outcome data to inform new treatment pathways and support personalisation. Each radiotherapy centre must generate their own local outcome data to inform discussions with patients about treatment options.

7. Embedding research activity into the radiotherapy service

Ensuring radiotherapy practice is at the forefront of innovation will require a dedicated focus to ensure research becomes an integral part of radiotherapy services. This will drive more clinical trial opportunities as well as service level innovations. All cancer areas should equitably benefit from further research, in particular brachytherapy and molecular radiotherapy.

8. A continued drive for cost efficiency

As well as improving patient outcomes, adoption of new radiotherapy techniques, clinical practices, and approaches is needed in order to streamline pathways, drive cost effectiveness, and release the resources for further investment.

9. Better public awareness of radiotherapy

With greater emphasis on increasing public awareness and understanding of the benefits of radiotherapy, more patients should have the opportunity to choose radiotherapy as a preferred treatment option.

APPENDIX C – Supporting research

Cancer research to date has led the way in developing clinical research infrastructure in the NHS. From the formation of the first cancer research network to current pilots looking to streamline the regulatory and governance processes across NHS Trusts, lessons learned from pioneering cancer research projects have benefits the whole healthcare system.

Commissioning to support research in the NHS

- Provider organisations are paid according to their ability to recruit a target number of patients. While there needs to be metrics to reward research active providers there are unintended consequence in this system. Organisations may see the cost benefits of recruiting large numbers into simple population-based or observational studies where patients are far more common, as more advantageous than recruiting patients for more complex, interventional trials which require fewer participants who are less common in the system but which need as much time and energy, if not more, to recruit to.
- Trials will continue to become more personalised and specialised across therefore more needs to be done to ensure that the value of this research is sufficiently captured and rewarded. This may involve mechanisms that reward delivery of smaller earlier phase trials.

Research workforce

Having a research active and aware workforce is the cornerstone to building a service where research forms a part of everyday work. There are numerous issues to address in order to achieve this including the time allowed for clinical research, research career pathways and research training.

1. Creating time for clinical research

- Clinical commitments and current service pressures on both people and physical capacity continue to create pressure on research. While pieces of infrastructure such as Biomedical Research Centres offer clinicians the ability to buy NHS sessions in their full time Programmed Activities to undertake research, the lack of certainty about funding can cause problems. Clinicians can be wary to lose session from the NHS Trust due to having concerns that if funding for their research sessions dries up then it will not be picked up again by the Trust.
- Clinical Excellence Awards continue to be a useful and important incentive to recognise clinical academics engaged in research. While there is uncertainty about the continuation of the awards, both financial and non-financial mechanisms for supporting and rewarding research engagement should continue to be considered.
- A mixture of disincentives and absence of incentives may prevent the clinical workforce becoming research active, this in turn effects the environment for research throughout the healthcare system.

2. Cancer research nurse career pathway

- The role of the clinical research nurse is central to research activity. In a recent study commissioned by CR-UK respondents stated that: *“the success or otherwise of research rested with this group of staff, and their ability to manage the necessary processes, recruit patients and maintain their involvement, and develop effective relationships with those staff that would be required to facilitate research activity.”*
- The role of research nurses should be celebrated and rewarded in the health service to ensure that studies are efficiently run and supported. From a career perspective, clinical research nurses saw themselves falling in a gap between a clinical and an academic career, with the former becoming increasingly distant from their experience as a nurse undertaking research, and the latter seen by some as moving too far away from contact with patients.

- A clearer career structure and greater certainty in contracts will support research nurses and allows the development of specialisation in the range of skills involved with research studies such as recruitment or writing grant applications.

Future needs of medical research

1. Precision medicine

- Bringing together many different technologies precision medicine aims to deliver the right treatment to the right person at the right time. This will be delivered through better understanding of a patient's and a tumour's specific genetic characteristics. The Government has committed to support a diagnostics in stratified medicine Catapult and a Stratified Medicine Consortium to help deliver on this agenda. In order for this investment to be fully realised the NHS must be set up to facilitate this form of research.
- As precision medicine could potentially lead to new models of care, researchers and clinicians suggested that accredited locations should be selected where new technologies, diagnostics, biomarkers and drugs would be studied, and best-practice protocols developed.
- These 'centres of excellence' should drive the appropriate levels of high quality science and innovation required, and would have access to the latest high-throughput sequencing technologies, data capabilities and expertise (in areas such as molecular pathology and bioinformatics). It was acknowledged, however, that centralisation was unlikely to be the optimal model indefinitely, and that it would be important for the major hubs to continually disseminate knowledge, protocols and guidelines to the wider cancer research community to enable smaller centres to deliver benefits to patients at a more local level over time.
- Molecular profiling is likely to become part of the standard care in issuing diagnosis, prognosis and treatment tailored to individual patients. Although the initial 'centres of excellence' will establish whether a centralised model or in-house expertise in each Trust would deliver the best model there will be a requirement to standardise the data analysis and read-outs nationwide. There was also agreement that solutions need to be driven on a national scale, and the NHS's role in driving this forward is key.

2. Increasing collaboration

- In order to translate research findings into treatments that benefit patients it will become increasingly necessary to work collaboratively across sectors and scientific disciplines. The health service must be aware of the changes to the way that science is operating and be open to trials being run in collaboration between charities and industry. These may pose specific issues around contracting and agreements between Sponsors and Trusts, while these issues may be resolved through the HRA single approval mechanism, Trusts should be aware of potential issues.

Case study: Cancer Research UK Clinical Development Partnerships

The CDD proactively looks for promising new drugs by working closely with the academic research community and the biotechnology and pharmaceutical industry. The CDD have developed successful business models to allow them to carry out research with an array of partners including biotechnology companies, academic institutions, specialised cancer groups and pharmaceutical companies. Their unique position of neutral charitable partner enables them to bring together competitor companies who allow access their drug development pipelines, so new combination therapy trials can be run. This means that new drug combinations can be tested much earlier, potentially speeding up the development of new treatments for people with cancer.

The Clinical Development Partnerships (CDP) is a joint initiative utilising the drug development experience of the CDD and the business development experience of Cancer Research Technology (CRT). The CDP initiative is targeted at biotechnology and pharmaceutical companies. The aim is to progress the development of

scientifically promising agents that have been de-prioritised by their parent company. These agents are not being actively developed, often for financial or strategic reasons. The CDP therefore provides new avenues and possibilities for treatments to reach patients

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