

# Improving Outcomes: A Strategy for Cancer

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# Foreword

The Coalition Government has set out a simple aim: to deliver health outcomes that are among the best in the world. To achieve this aim, we have set out radical plans for the health and social care services. These plans are underpinned by three, mutually-reinforcing principles:

- to put the patient or service user at the heart of the public services – transforming the relationship between citizen and service through the principle of *no decision about me without me*;
- to orientate the NHS, public health and social care services towards delivering the improvements in outcomes which matter – rather than measuring processes which do not; and
- to empower local organisations and professionals to deliver the freedoms to innovate and to drive improvements in services which deliver care of the highest quality for all patients and service users.

In order to achieve these principles we must also ensure that every possible penny of money the NHS has is spent improving the quality of care and outcomes that patients experience. The Government protected the NHS in the Spending Review settlement, with cash funding growth of £10.6bn (over 10%) by 2014/15. Compared to many other government departments, that puts us in an incredibly privileged position but this is the toughest settlement the NHS has faced in a long time.

At the same time we need to respond to the longer term pressures the NHS faces; of an ageing population and the new demands created by new treatments and technologies. That means that, as set out in the Spending Review and the 2011/12 Operating Framework, over the next four years the NHS will need to achieve up to £20bn of efficiency savings. These savings will be reinvested back in continuing to give patients the care that they need.

We know that it is possible to achieve efficiency savings and improve the quality of services at the same time and that cancer services can make a significant contribution to meeting the quality and productivity challenge the NHS has been set. For example, we know that offering appropriate patients the opportunity to have their breast cancer treated as a day case or on a 23-hour pathway rather than as an inpatient improves their experience and reduces their length of stay saving commissioners money.

We also know that, in the outcomes of cancer care, we are failing to achieve our aim. Our record is one of delivering health outcomes which fail to match those achieved by the best-performing countries, or even average-performing countries. Although significant improvements have been made in recent decades – and we welcome the work of all those involved in driving these improvements – outcomes for patients in England continue to lag behind those in countries of comparable wealth. The National Audit Office reported recently that almost one in four cancers are detected only when a patient is admitted to hospital as an emergency.<sup>1</sup> Our survival rates for cervical, colorectal and breast cancer are amongst the worst in the Organisation for Economic Co-operation and Development (OECD). Higher morbidity and mortality in disadvantaged groups and areas are a key driver of our poor average outcomes.

Governments of the past have placed too much faith in the ability of a top-down hierarchy to deliver improved results for patients, through the micro-management of services from Whitehall resulting in the disempowerment of frontline staff and the disenfranchisement of patients. Too little faith has been placed in the power of local communities and frontline clinicians – and patients and service users themselves – to drive the improvements that we need to see.

That is why this Outcomes Strategy is needed. It translates the three underpinning principles of the Coalition Government's reforms of the health and care services into the steps we need to take to drive improvements in cancer outcomes.

In order to put patients, service users and members of the public at the heart of decisions about their care, this Strategy:

- sets out the actions we will take to tackle the preventable causes of cancer, by providing better information to people about risk factors and how individuals and communities might work to minimise them, as well as the steps we will continue to take to improve the experience of cancer patients and support the increasing number of cancer survivors;
- describes the ways in which choice for patients in their cancer care will be extended and implemented throughout the health and social care systems, informing both the decisions taken by NHS organisations now and the methods through which the mandate for the NHS Commissioning Board may be discharged; and
- identifies the gaps in information on health outcomes which are crucial to ensuring patients are empowered – in consultation and with the support of their clinicians – to exercise real choice over the care they receive, including through the extension of national clinical audit and through the strengthened patient voice delivered by HealthWatch (Note: all new data collections proposed in this

Strategy are subject to the appropriate approvals from the Review of Central Returns – ROCR, the Information Standards Board – ISB, and the National Information Governance Board – NIGB)

In order to ensure that health and care services are orientated towards delivering the improvements in outcomes for people with cancer we wish to see, and prioritised through the high-level outcomes contained in both *Transparency in outcomes: NHS Outcomes Framework 2011/12*<sup>2</sup> and *Healthy Lives, Healthy People: Transparency in Outcomes*,<sup>3</sup> this Outcomes Strategy:

- sets out the work which the public health service will be charged with undertaking to deliver the necessary improvements in prevention, raising awareness of cancer symptoms and achieving earlier diagnosis, and the resources it will have at its disposal to deliver this work;
- outlines the resources the NHS Commissioning Board will be able to draw on to drive improvements in the quality of NHS cancer commissioning – including commissioning support packs, NICE Quality Standards, and appropriate indicators which commissioners may wish to include in their incentive payments for providers; and
- identifies ways in which best practice approaches to cancer commissioning can be disseminated for use by pathfinder consortia through the transition and beyond.

In order to empower local organisations and frontline professionals to encourage the delivery of improved cancer care, this Outcomes Strategy:

- provides possible future models for the delivery of advice and support on cancer commissioning at the national level, in particular by exploring ways in which the National Cancer Action Team and cancer networks might best offer their support to providers and commissioners through a more flexible, social enterprise-based approach;
- reports on the review of cancer waiting time standards, recommending that current cancer waiting time standards are retained by commissioners for the foreseeable future and used as the basis on which the framework of outcomes and quality standards can further strengthen patients' timely access to services; and
- announces plans to harness the innovation and responsiveness of the charitable sector further in cancer care, both to build on the important work done to date to promote healthier lifestyles, encourage earlier diagnosis and provide information and support for those living with cancer, but also to broaden this

important work out to encompass services which the voluntary sector may provide directly to GP consortia and to providers, both through the transition period and beyond.

This Outcomes Strategy sets out how – in cancer care – we will bring the approach we have set out for the health and care services to bear in order to improve outcomes for all cancer patients and achieve our specific aim of improving cancer survival rates. Through the approaches this Strategy sets out, we aim to save an additional 5,000 lives every year by 2014/15, aiming to narrow the inequalities gap at the same time.

### About outcomes strategies

This is the first of a number of outcomes strategies which will set out the ways in which we will meet our aim of delivering healthcare outcomes as good as anywhere in the world.

Outcomes strategies set out, for a particular service area:

- our ambitions for the quality of services we want to make available to patients and service users, and to their carers and families, without exception;
- the support, information and choices which patients and service users, and their carers and families, will receive to make best use of these high-quality services;
- the ways in which these services will be held to account for the outcomes they deliver through the NHS, social care and public health outcomes frameworks;
- the support which the Government will provide to assist these services to meet the outcomes for which they are accountable; and
- the work which the Government will lead with non-state sectors to help shape services that meet the needs of patients and service users.

Outcomes strategies set out how the NHS, public health and social care services will contribute to the ambitions for progress agreed with the Secretary of State in each of the high-level outcomes frameworks:

- where only the NHS needs to be involved in improving outcomes in a particular area, the relevant outcomes strategy will be initiated and its development led by the NHS Commissioning Board; and
- where integrated action is required across any combination of the NHS, public health and social care services to improve outcomes in a particular area, the relevant outcomes strategy will be initiated and its development led by the

Department of Health, in conjunction with Public Health England and the NHS Commissioning Board as appropriate.

During the transition to the new structures, the Department of Health will lead on the development of all outcomes strategies, taking account of the NHS Commissioning Board's and Public Health England's input as they emerge in shadow form. Primary Care Trusts (PCTs) will continue to take responsibility for delivering on improved outcomes for their patients until they are abolished, and their functions in the relevant area transferred to consortia, local authorities and the NHS Commissioning Board.

Outcomes strategies reject the top-down approach of the past which has stifled innovation and creativity. Instead, they focus on how patients and service users can best be empowered to make the right care decisions themselves, and on how clinicians on the frontline can best be supported to deliver what matters to patients and service users: high-quality and improving outcomes.

Outcomes strategies recognise that government can achieve more in partnership with others than it can alone. They establish and build on the platforms of joint working which exist across central government – and between government, local organisations, and patient and professional groups – to harness the creativity and innovation which exist across our society in pursuit of our ambitions for the health and social care services.

This outcomes strategy is being published at a time of transition. The Health and Social Care Bill, to be introduced into Parliament in January 2011, will take forward a number of structural changes designed to underpin the Government's reforms to health and social care. As such, those changes will require primary legislation. Where this document refers to the new structures, these are the Government's current intentions for those bodies, subject to Parliamentary approval.



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Secretary of State for Health



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Minister of State for Care Services

# 1. The challenge of cancer

## Introduction

1.1 This chapter sets the context for this Strategy. It looks at:

- the issues that we are tackling;
- what the public, patients, their carers and clinicians want in relation to cancer services;
- the new evidence that has arisen which informs the development of our plans;
- the need for, and the scope to deliver, efficiency savings;
- how the Big Society can help us;
- promoting cancer research; and
- how, moving forward, we will provide central support in the transition to help improve outcomes

## What are we tackling?

1.2 Cancer affects all of us. Over 250,000 people in England are diagnosed with cancer every year and around 130,000 die from the disease. Currently, about 1.8 million people are living with and beyond a cancer diagnosis. Even if we do not develop cancer ourselves, we all have family and friends who have had cancer. Surveys show that people fear cancer more than anything else.

1.3 Despite improvements in survival and mortality in recent decades, cancer outcomes in England remain poor when compared with the best outcomes in Europe. Although improvements have been made in the quality of cancer services, a significant gap remains in both survival and mortality rates. To put this in context, if England was to achieve cancer survival rates at the European average, then 5,000 lives would be saved every year. If England was to achieve cancer survival rates at the European best, then 10,000 lives would be saved every year. That is our challenge. There is a range of action needed to respond to this but, in particular, we need to:

- reduce the incidence of cancers which are preventable, by lifestyle changes;

- improve access to screening for all groups and introduce new screening programmes where there is evidence they will save lives and are recommended by the UK National Screening Committee;
- achieve earlier diagnosis of cancer, to increase the scope for successful treatment – diagnosis of cancer at a later stage is generally agreed to be the single most important reason for the lower survival rates in England; and
- make sure that all patients have access to the best possible treatment.

1.4 And there are challenges in addition to the delivery of improved survival and mortality rates, in particular:

- many patients live with and beyond cancer for long periods of time, and we need to ensure that everything is done to allow them to live as healthy a life as possible, for as long as possible;
- there are variations in patients' experience of care, and we need to make sure that feedback on patient experience informs the design and delivery of services so they reflect what is important to all patients; and
- inequalities in cancer mean that some groups in society have disproportionately poor outcomes.

1.5 As well as having a devastating human impact, cancer also has a significant financial impact on the NHS and the wider economy. In 2008/09, it is estimated that NHS expenditure on cancer services was over £5.1 billion (and the National Audit Office (NAO) has estimated that expenditure is actually around £6.3 billion), making it the third largest area of programme expenditure. The total cost of cancer to society as a whole has been estimated at £18.3 billion for the same year.<sup>4</sup> These costs are set to rise still further as incidence increases, people live for longer with cancer and new treatments become available.

1.6 While recognising that there have been considerable improvements in cancer services and outcomes over the last decade, the Coalition Government now wants to take further steps to tackle preventable incidence, to improve the quality and efficiency of cancer services and to deliver outcomes which are comparable with the best in Europe. This Strategy sets out how we will make progress towards this, both in terms of the reforms described in *Equity and excellence: Liberating the NHS*<sup>5</sup> (and subsequently in *Liberating the NHS: Legislative Framework and next steps*<sup>6</sup>) and *Healthy Lives, Healthy People: our strategy for public health in England*<sup>7</sup> – and associated documents – and, more immediately, before those reforms have been fully implemented.

- 1.7 Large numbers of organisations and individuals have been involved in the development of this strategy. Details of this engagement are set out in Annex A. We are very grateful to all who contributed.

### What the public, patients, carers and clinicians want

- 1.8 The Coalition Government will put the public, patients and their carers at the heart of cancer services and will empower clinicians to deliver services of the highest quality. So, we begin by setting out in broad terms what we think those groups want from cancer services.

### What are individual members of society and the public likely to want with regard to cancer services?

- 1.9 The public's wishes are likely to include:
- information and advice on how to reduce their risk of cancer;
  - access to services (eg stop smoking services) which can help them reduce their risk of cancer;
  - information on the symptoms and signs of cancer, so that they can seek help early if problems arise and thereby improve their chances of cure;
  - balanced information on screening programmes so that they can make informed choices;
  - access to high quality screening programmes which can prevent cancer or catch it early before it causes symptoms; and
  - the reassurance that if they or their relatives do develop cancer they will have rapid access to high quality services which deliver outcomes which are amongst the best in the world.

### What are cancer patients and their carers likely to want?

- 1.10 Cancer patients and their carers are likely to want:
- good access to assessment and diagnostic services which can either exclude cancer or make the diagnosis without delay;
  - access to reliable and balanced information about their condition, possible treatments and side effects, so that they can make choices which are appropriate for them;
  - easy access to comprehensive information about the services available to them and the outcomes achieved by these services;

- to be empowered to make choices where these are clinically appropriate and to be supported in decision making to the extent that they wish;
- to know that the best treatments will be available to them. If the NHS cannot provide treatments because they do not offer value for money, they will be told about this and will be able to pay for such treatments themselves without losing their right to NHS care;
- to know that they will receive the support they need (physical, emotional, social and financial) through their treatment;
- to be treated as a whole person, not just a “set of symptoms”;
- to know that everyone involved in their care has the necessary training and expertise;
- to be reassured that everyone involved in their care will work effectively together, so that their care will feel seamless even when delivered in different locations;
- to be told about relevant clinical trials when considering treatment;
- to know that at the end of treatment they will be:
  - supported to regain as normal a life as possible;
  - given advice about how to minimise their risk of developing further cancer-related problems;
  - given advice about possible signs of recurrence or long-term effects of treatment; and
  - able to re-access specialist services without delay should they need to do so;
- to know that if they do develop progressive or advanced cancer they will be supported through this and have access to the best treatments; and
- to know that if they are approaching the end of life their preferences for care will be discussed with them and every effort will be made to meet their needs and their preferences for care.

## What are health professionals involved in the prevention, diagnosis, treatment and care of cancer likely to want?

1.11 Healthcare professionals are likely to want:

- the training, support and information they need to deliver high quality care;
- to work in a team that has all the necessary expertise to deliver good outcomes;
- to work in state of the art facilities and have access to proven modern technologies and equipment;
- to work in a service which is well managed, so that their time is used effectively and so that care is streamlined for patients;
- to be able to compare the outcomes they achieve with those achieved elsewhere in this country and in other developed countries; and
- to be free to make the clinical choices which they feel will benefit their patients the most.

## New evidence

1.12 Importantly, this Strategy has also been informed by the evidence and analyses that have become available in recent months. These include:

- a new international benchmarking project – findings from which suggest that English survival rates continue to lag behind the best performing countries in the partnership and that, with the exception of breast cancer, we are not narrowing the “survival gap” to move closer to the best performing countries;<sup>8</sup>
- an analysis of variations in drug usage across a number of different countries – which shows that the UK has a low rank for the most recently licensed cancer drugs;<sup>9</sup>
- research into the way in which patients are first diagnosed with cancer – which shows that about a quarter of cancer patients are diagnosed via emergency routes and that the survival rates for those diagnosed via emergency routes are considerably lower than for other cancer patients;<sup>10</sup>
- a review of the quality of cancer registration – phase one of which concluded that deficiencies in cancer registration do not explain the differences in survival rates that have been observed;

- results from clinical trials of screening – for example new research shows that a one-off procedure using flexible-sigmoidoscopy to screen for bowel cancer could save 3,000 lives per year;<sup>11</sup>
  - measurement of service quality through peer review – which shows that performance is improving overall but is unacceptable in a small number of multidisciplinary teams;<sup>12</sup> and
  - a new cancer patient experience survey – which demonstrates which areas require more attention to improve patient experience.<sup>13</sup>
- 1.13 In addition, the Strategy has built strongly upon a recent report by the NAO on the implementation of the Cancer Reform Strategy (CRS). This looked at the use of information and commissioning to deliver the CRS, and at value for money in the delivery of cancer services.
- 1.14 More information about this new evidence is set out in Annex B.

### Efficiency savings

- 1.15 The outcomes articulated in this Strategy will need to be realised within the context of the tighter financial environment ahead, with the ambition of achieving efficiency savings of up to £20 billion for reinvestment over the next four years. This represents a very significant challenge but, through the detailed work the NHS has already undertaken on Quality Innovation Productivity and Prevention (QIPP) and the additional opportunities presented in the *Equity and Excellence: Liberating the NHS*, we believe the required savings and improvements can be achieved.
- 1.16 Through the Spending Review, the Government protected the NHS, with cash funding growth of £10.6bn (over 10%) by 2014/15. By comparison with other departments, this is a generous settlement. Nevertheless, by historical standards this remains extremely challenging.
- 1.17 This is in the context of an ageing and growing population, new technology and higher patient expectations, all of which mean that underlying demand continues to grow rapidly.
- 1.18 In relation to the QIPP challenge, the NHS has been developing proposals to improve the quality and productivity of its services since the challenge was first articulated in May 2009. The White Paper *Equity and Excellence: Liberating the NHS* represents an opportunity to support the NHS to do this more effectively. We are bringing together the existing planning and implementation of QIPP and the implementation of the White Paper to form one integrated and mutually reinforcing programme of work that

exploits the additional opportunities for increased quality and productivity set out within the White Paper reforms. This will help manage the risks and keep the focus on delivery at the same time as reconfiguring the system.

Early examples of this include:

- local and regional organisations producing one QIPP and Reform plan to oversee the implementation of QIPP and *Equity and Excellence: Liberating the NHS*;
- ensuring that active ownership of the QIPP agenda is a criterion for selection as a GP consortia pathfinder; and
- placing QIPP plans at the centre of the assessment of the business plans for acute trusts applying for Foundation Trust status.

1.19 Realising these savings will help us fund new policy commitments as we move through these challenging times.

1.20 In thinking about how best to deliver efficiency savings over the coming years, commissioners will also wish to note the three areas for potential savings highlighted in the NAO report:

- use of radiotherapy machines varies over twofold per year, per machine, by centre. While there may be valid reasons for these variations, the NAO identified potential for existing capacity to be used much more productively;
- inpatient admissions per new cancer diagnosis varied from 1.7 to 3.2 between PCTs in 2008/09. If every PCT met the inpatient admissions per new cancer diagnosis of the best performing quartile, 532,000 bed days could be saved, equivalent to around £106 million each year; and
- average length of stay for inpatient cancer admissions varied from 5.1 to 10.1 days between PCTs in 2008/09. If every PCT had the same length of stay as the average for PCTs in the best performing quartile, then even with no overall reduction in inpatient admissions, 566,000 bed days could be saved, equivalent to around £113 million each year.

1.21 Variations in the number of cancer bed-days and inpatient expenditure were highlighted in the NHS Atlas of Variation.<sup>14</sup> The data used in the cancer maps in the NHS Atlas of Variation has been adjusted for age, sex and need, suggesting that commissioners in some areas have significant scope for reducing elective bed day usage and expenditure. The Atlas highlights some potential resources which commissioners may wish to use to address unwarranted variation.

## A Big Society approach to tackling cancer

- 1.22 The state, as the funder of NHS cancer services, will always have a significant role to play in leading the fight against cancer and it is right that it should do so. However, working together with other organisations and individuals we can make an even bigger difference in the fight against cancer:
- cancer charities raise awareness of cancer, raise money to fund research and services, deliver some services, including information, and campaign for change;
  - academic institutions undertake research into all aspects of cancer, including basic science, prevention, early diagnosis, treatment and the psycho-social effects of the disease;
  - bioscience companies develop new tests and treatments for cancer;
  - some major commercial companies partner with cancer charities to raise funds to tackle cancer;
  - hospices support those nearing the end of their life; and
  - thousands of people affected by cancer support each other both informally and through support groups.
- 1.23 Much of society is already involved in supporting cancer care and research, but we can extend these activities, so that every part of society plays its part, from raising awareness to helping fund research or supporting people affected by cancer. Adopting a Big Society approach can harness the resources, talents and expertise of all groups in society. This should enable messages and support on cancer to reach and engage with people in a way that Public Health England or the NHS alone would not be able to do. We will take a Big Society approach in cancer by:
- empowering individuals and communities;
  - encouraging social responsibility; and
  - creating an enabling and accountable state.
- 1.24 There is a range of inspiring examples of different groups in society coming together to tackle cancer. However, more can be done to support society in playing its part. The Government will therefore facilitate the development of

a national partnership. This will enable organisations who wish to play their part in tackling cancer to do so. Participating organisations will be asked to:

- support and enable the public and/or employees to reduce their risk of cancer by creating a healthier environment;
- raise awareness of the signs and symptoms of cancer, enabling employees and/or customers to seek earlier help;
- make it easier for employees to participate in cancer screening programmes by providing flexible working arrangements for screening appointments;
- adopt “cancer friendly” policies and practices for employees affected by cancer, where possible supporting them in staying in or returning to work;
- signpost employees and/or customers to appropriate information and support on cancer, ensuring that no one affected by cancer feels that they do not know where to turn for support; and
- utilise their unique relationship with employees and customers to enable everyone to play their part in delivering better cancer outcomes.

1.25 The partnership will not seek to raise funds for cancer or to duplicate or replace existing activity and partnerships. Instead it will seek to stimulate new community action to improve outcomes and support patients. Participating organisations will receive expert advice from the current partnership initiatives within the Cancer Programme – the National Awareness and Early Diagnosis Initiative, the National Cancer Equality Initiative and the National Cancer Survivorship Initiative.

1.26 Organisations of every size will be encouraged to join the partnership, from small businesses such as hairdressers to major employers such as supermarket chains, providing that their business activities do not conflict with the objective of improving cancer outcomes. The DH will work to develop this partnership over the coming year.

## Research

1.27 *Equity and excellence: Liberating the NHS* makes clear the Government's commitment to supporting excellent research. The National Institute for Health Research (NIHR) provides the NHS with the support and infrastructure it needs to conduct first-class research. A wide range of

research will be critical to reducing the burden of cancer and to improving cancer outcomes. The Government will work with partners such as Cancer Research UK to support basic research into how cancer starts and develops; clinical and translational research so that discoveries can move quickly from bench to bedside; research into prevention, screening and epidemiology; health services research; and research to support those living with cancer and those nearing the end of life.

- 1.28 Future cancer research in this country will build on firm foundations. The National Cancer Research Institute (NCRI), of which DH is a member, brings together all the key partners in cancer research. The NCRI coordinates research initiatives on prevention, awareness and early diagnosis, survivorship and radiotherapy. The NIHR National Cancer Research Network (NCRN), combined with additional funding for clinical trials from Cancer Research UK and others, has led to a quadrupling of entry of cancer patients into clinical studies, making this country a world leader. The National Cancer Intelligence Network (NCIN) provides an excellent platform for epidemiological and health services research.
- 1.29 Given the importance of early diagnosis in improving cancer outcomes, DH's Policy Research Programme will provide funding from January 2011 for five years for a policy research unit on Cancer Awareness, Screening and Early Diagnosis. In addition over the next 18 months, the International Cancer Benchmarking Partnership, which is led by DH, will provide insights that will help us understand survival differences between countries and thus to take steps to address them.

### Central support for moving forward

- 1.30 As set out in this Strategy, the Coalition Government's reforms will provide the levers for delivering the services and outcomes which patients and the public want. Local action by healthcare professionals, free to innovate and respond to the needs of patients, will be critical to achieving our outcome goals.
- 1.31 In addition, national leadership, through the National Cancer Director, will remain important to deliver this ambitious Strategy. An Implementation Advisory Group (IAG) comprising key stakeholders, including commissioners and patient representatives, will be established to help monitor delivery of this Strategy.
- 1.32 Our health service is in transition. As new structures such as GP consortia, health and wellbeing boards and the NHS Commissioning Board are established, the IAG will play a crucial role to ensure that commissioners,

providers, regulators and those overseeing healthcare are equipped with the expertise and support they need to deliver high quality cancer services.

- 1.33 Until the new NHS structures are in place, the implementation of the first stages of this Strategy will be supported by the bodies that make up the National Cancer Programme: the National Cancer Action Team (NCAT), NHS Improvement and the National Cancer Intelligence Network (NCIN). Over the transition period, these bodies will need to consider how they can best align themselves with the new structures and arrangements. Our view is that NCAT and NHS Improvement may well wish to turn into social enterprises, but that the NCIN is likely to need to continue to be funded by a mix of statutory and voluntary sources. NHS Cancer Screening Programmes will be the responsibility of PHE, but in clinical terms remain a key part of the cancer pathway.
- 1.34 Commissioners and providers are currently supported by cancer networks. It is very likely that GP consortia will wish to purchase support from a new style of cancer network. In the transitional period, we will fund cancer networks to support the GP consortia.
- 1.35 Assessing progress on delivery of this Strategy during transition and beyond will be important. Annual reports will be published to measure progress on implementation and on improving cancer outcomes.

## 2. Putting patients and the public first: information and choice

### Introduction

- 2.1 Information will be central to the drive for better outcomes. Better information underpins stronger commissioning and patient choice, helping the public to make the right decisions to reduce their risk of cancer and to support them in accessing screening, diagnosis, treatment and survivorship care. Information also enables commissioners to drive up the quality of services and outcomes and to make efficient use of resources.
- 2.2 We are committed to creating a presumption of choice, including choice of treatment and any willing provider across the vast majority of NHS-funded services by 2013/14. This chapter considers what that will mean for cancer services.

### The information revolution in cancer

- 2.3 *Liberating the NHS: An Information Revolution*<sup>15</sup> makes it clear that:
- patients must have the information they need to make the right choices about their health and treatment;
  - the NHS and social care must have the information they need, appropriately analysed by inequality/equality group, to enable them to make the right decisions around commissioning and providing quality services; and
  - the public must have the information they need to make the right choices about healthy lifestyles.
- 2.4 In line with this, high quality cancer services depend on having accurate, relevant, contextualised, timely and accessible information available to help patients, commissioners, providers, clinicians, researchers and those seeking to scrutinise health services. To be effective, information must be:
- informing, so that they know it is comprehensive and can be trusted;
  - engaging, so that they are willing and able to use it; and
  - empowering, so that they know how it can make a difference.

- 2.5 While we cannot pre-empt the outcome of the consultation on *An Information Revolution*, we are confident of the general direction of travel. Encouraging progress has already been made in improving the range, quality and timeliness of analyses about cancer services which are available. The National Cancer Intelligence Network (NCIN) – a partnership of organisations from the public and voluntary sectors who are working to provide analyses to support better cancer services and outcomes – has linked a range of existing national datasets enabling new insights to be generated, as well as streamlining the way in which information is collected. Much of this information has been made available to support commissioners and inform providers. However, there is more to do, both in encouraging the timely availability of information and in stimulating its use to improve patient care. Where this strategy proposes new data collections or datasets these will be subject to the appropriate Review of Central Returns (ROCR) and the Information Standards Board (ISB) approvals prior to commencement.
- 2.6 In the future, the Health and Social Care Information Centre (HSCIC) will have a key role in publishing raw data which will be available for a range of different organisations to use. NCIN will continue to work with the HSCIC to provide analyses to help improve services and outcomes.
- 2.7 Quality Accounts provide a mechanism to help providers identify and focus on the issues which will make the biggest difference to the quality of care they provide, as well as providing an opportunity to explain to commissioners, patients and the public which issues have been prioritised and how the organisation will set about addressing them. In June 2010, acute providers published the first Quality Accounts. They are public reports by NHS organisations about the quality of healthcare services they provide.
- 2.8 The Quality Accounts published in 2010 have varied in the way in which providers have reported the quality of their services. Following the evaluation of the 2009/10 Quality Accounts, the lessons learned are that Quality Accounts have been an effective tool for raising the profile of quality improvement and engaging Boards. As organisations gain experience in this type of reporting, their Quality Accounts will be more effective at explaining to patients how key services such as cancer are being improved. In 2011, we will produce a guide for cancer networks to enable them to help providers to raise their game in understanding and reporting on cancer services.

2.9 Moving forward, and taking on board the comments made by the NAO and the Public Accounts Committee, our priorities for 2011/12 will include:

- collating and publishing high quality information that commissioners and providers need about incidence, prevalence and survival, as a basis for planning services;
- collating and publishing high quality information on different aspects of cancer services and the outcomes they deliver at both a provider and a commissioner level;
- investigating different aspects of cancer care so that trends, patterns and good practice may be identified;
- working with regulators to ensure that the information on cancer services which is collected is used to inform effective regulatory oversight and, where necessary, action;
- improving the quality of the data which underpins expenditure information on cancer services;
- providing transparent information so that policy makers and others may scrutinise the quality of cancer services by inequality/equality group; and
- encouraging other organisations, such as cancer charities, to provide information to patients and carers and to help them make informed choices.

2.10 In addition, in 2011/12 we will pilot the collection, through cancer registries of data about metastatic disease. While we know that almost half a million women are living with and beyond a diagnosis of breast cancer, we do not know what proportion of those have metastatic breast cancer and, without this information, it is impossible for the NHS effectively to plan the services they need. Cancer registries have historically collected information on diagnosis, treatments given in the first year after diagnosis and survival, but have not collected information on date of recurrence or secondary spread. This means that it is not possible to estimate prevalence of metastatic disease accurately or undertake other important analyses on patients with secondary cancer. During 2011/12 we will pilot the collection of data on recurrence/metastasis on patients with breast cancer with the aim of undertaking full collection from April 2012. The learning from this exercise will, in time, be applied to the collection of information on other forms of metastatic cancer.

- 2.11 Once the NHS Commissioning Board is established it will need to assess the information needs in relation to cancer, but we would expect that it would wish to build on the work planned for 2011/12.
- 2.12 In moving forward, we need to ensure that analyses are provided that are important for the public as well as for commissioners and providers, such as:
- the range of cancer services provided by each Trust;
  - whether each team has core members from all the relevant disciplines;
  - whether the team has a clinical nurse specialist;
  - how many patients by equality characteristic were diagnosed/treated in the previous year;
  - compliance with waiting time standards;
  - compliance with peer review measures;
  - major resection rates; and
  - mortality rates within 30 days of treatment.

The public will also wish to see the results of patient experience surveys – see chapter 5.

- 2.13 Accurate, tailored, timely and accessible information is vital to providing a good patient and carer experience. This, combined with involving people in decisions about their own care through personalised care planning and offering real choice for patients over where, how and by whom they are treated, forms a key plank of the Government's reforms of the NHS. Carers will also need information, advice and support to carry out their caring role effectively. Many of them will not know about the wide range of advice and support that is available for those with caring responsibilities and they should be signposted to such help. Better information should also help to reduce health inequalities by reducing the knowledge deficit that can exist in healthcare.
- 2.14 Information prescriptions guide people to relevant and reliable sources of information to allow them to feel more in control, better able to manage their condition and maintain their independence. The National Cancer Action Team (NCAT) in partnership with Macmillan Cancer Support and Cancer Research UK is now supporting the use of information prescriptions so that every cancer patient in England should be able to benefit over the lifetime of this Strategy. Work will continue to develop the use of information prescriptions throughout the cancer pathway.

- 2.15 Information is also important for patients to help them reduce their risk of developing cancer. Most people know that smoking causes lung cancer and sunburn causes skin cancer. However, far fewer people know that a poor diet, obesity, lack of physical activity and high alcohol consumption are also major risk factors for getting cancer. Public Health England (PHE) nationally and locally will provide people with information about these risk factors so they can make healthy choices.

### Using information to reduce inequalities

- 2.16 It will be impossible to tackle inequalities effectively without the appropriate data to inform activity and scrutinise progress. The National Cancer Equality Initiative (NCEI) has established a baseline from which to measure improvement, an agreed basket of equality metrics and an understanding of how to close the inequality/equality gaps.
- 2.17 The equality metrics are being used nationally and locally to track progress and consider improvements to cancer services, and have been disseminated through the Equalities Portal (<http://www.ncin.org.uk/equalities/>). The Portal is an early example of how the principles of the information revolution can be applied to cancer services, enabling commissioners to understand better their health outcomes, providers to target improvements and stakeholders to hold services to account for the outcomes which matter most to patients.
- 2.18 Further analyses to inform the equality agenda are planned on rarer cancers, access to cancer treatment and outcomes for people with mental health problems, as well as examining survival, mortality and incidence by geographical area. We will continue to publish one-year survival data to identify which groups are more likely to present late.

### Expanding patient choice

- 2.19 *Liberating the NHS: greater choice and control*<sup>16</sup> is based on patients being at the heart of decision-making in the NHS. *No decision about me without me* should be a guiding principle in the delivery of all treatment. The report envisages a presumption of choice and any willing provider across the majority of NHS-funded services by 2013/14. In cancer, a range of different forms of choice are relevant, including:
- when to have treatment;
  - where to have treatment (some treatments can be given in hospital or in the community);

- which organisation delivers treatment and care;
- which team delivers the treatment; and
- what form of clinically appropriate treatment to have.

2.20 The choices that cancer patients should be able to make will not always be straightforward. Exercising informed choice requires a patient to have the right information and support available to make the most appropriate decision for their own circumstances. It will be critical that healthcare professionals have adequate communication skills to support patients in making decisions and that this is supported by the provision of high quality, tailored written information.

2.21 We cannot pre-empt the outcome of the consultation on *Liberating the NHS: greater choice and control*, but we envisage that:

- commissioners will seek to maximise the choices which patients can make at the point of urgent referral by a GP, whilst recognising that pooled referrals are critical to ensuring speedy access to a first appointment with a specialist;
- apart from at that initial stage, the guiding principles in relation to cancer will be the same as for most other NHS services – patients will be able to elect to receive care from any organisation in England that offers a service that is clinically appropriate for them, meets the essential levels of safety and quality expected from providers of NHS-funded services (including relevant guidance on appropriate levels of specialisation), and can deliver services within NHS prices, and there will be a choice of named consultant-led team by April 2011.

2.22 Applying choice across the pathway will be important for cancer as patients may wish to choose different providers for different forms of treatment and care. For example, a patient may be prepared to travel further for surgery from a specialist provider with better outcomes, but may wish to receive treatments such as chemotherapy and radiotherapy closer to their home. Others may prefer to travel but might face barriers which prevent them from doing so and some patients may prefer the benefits of the close working relationships developed between service providers within an area. Effective choice should not involve a series of one-off decisions but rather a process of continuous patient engagement with entitlements to revisit decisions provided it is clinically appropriate.

2.23 In cancer, decisions about which treatment to have can be finely balanced, with different options having different advantages and drawbacks. In these circumstances it is important that patients and carers have information they

understand and are closely involved in making decisions. Where there is a range of different, clinically appropriate and evidence-based treatments available, people should be able to choose the treatment that is right for them, supported by accessible information about the treatments, risks, any side-effects and supportive care. They should also be able to choose to decline treatment. The consultation response will set out more detailed proposals on how choice of treatment will work in practice.

- 2.24 There are certain services which some hospitals provide and others do not, and we believe it is very important that patients are given the option to go to the hospital that provides the service they think is best for them. In particular, all patients should be told, when relevant, which hospitals provide:
- laparoscopic versus open colorectal cancer surgery;
  - immediate versus delayed (or no) breast reconstruction;
  - surgery, radiotherapy, active monitoring or other treatments for localised prostate cancer; and
  - Intensity Modulated Radiotherapy (IMRT).
- 2.25 For patients nearing the end of their life, it is important that they are given a choice about where they die. Most deaths occur in hospital, but, when asked, most people say they would like to die at home in familiar surroundings, close to family and friends. Changing this will require improving the support which is available in the community. A national choice offer will be established for those people who choose to die at home (including a care home) to receive the support that they need. A review will be undertaken in 2013 to determine when this offer should be introduced.

### Helping patients and the public have a voice in cancer services

- 2.26 As well as extending choice, it is important that patients and the public have a voice in how cancer services develop. *Liberating the NHS: Equity and Excellence* set out proposals to establish HealthWatch as a national and local consumer voice championing the views and experiences of patients. The Government's response to the consultation on these proposals, *Liberating the NHS: Legislative framework and next steps*, recognised the importance of HealthWatch England having a stronger identity to strengthen the patient voice. This will of course be relevant for all cancer patients.

- 2.27 Local HealthWatch organisations will have an influential role in helping to shape services by being involved in commissioning decisions and in strengthening engagement by working with local community-based groups and networks. Their role will be enhanced through proposals for local HealthWatch to have a place on the local health and wellbeing boards, and will have a distinct role within the Care Quality Commission to strengthen the patient voice. In addition, local HealthWatch will be able to raise issues with HealthWatch England which can provide advice to the Secretary of State, NHS Commissioning Board and regulators.
- 2.28 There is also a role for cancer-specific involvement in partnership with professionals. Cancer networks have made good progress in encouraging effective user involvement in the development of cancer services. Many cancer charities have also developed programmes to encourage greater patient involvement in NHS cancer services. This form of involvement can be invaluable in ensuring that patients' perspectives are used to inform the development of services. Building on the broader work on patient and public engagement, during the transition period cancer networks will be able to support consortia in developing cancer user involvement mechanisms, ensuring that the experience of recent years is built upon.

## 3. Improving outcomes for cancer patients: an introduction

### Introduction

- 3.1 This chapter looks at what the Coalition Government's reforms will mean for improving cancer outcomes in general. Chapters 4, 5 and 6 look at improving outcomes at different points in the patient pathway, whilst chapter 7 looks at improving outcomes by reducing inequalities.
- 3.2 The reforms set out in *Equity and Excellence: Liberating the NHS* and in *Healthy Lives, Healthy People* will help to achieve better outcomes by devolving power and freedoms to frontline clinicians and to local government, by making the service more responsive to patient choice, and by establishing a renewed focus on improving public health. The current performance regime will be replaced with outcomes frameworks that set direction for the NHS, public health and social care which provide for clear and unambiguous accountability. Given that the cancer pathway spans the NHS, public health and social care, all three frameworks will address issues of relevance to the condition.

### NHS outcomes

- 3.3 The primary purpose of the NHS is to deliver good healthcare outcomes for all: to deliver care that is safe, effective and provides the best possible experience for patients. Achieving improvements in these core outcomes will be the objective of the NHS Commissioning Board which will be held to account by the Secretary of State for Health.
- 3.4 *Transparency in outcomes: NHS Outcomes Framework 2011/12* provides direction for the NHS. It includes a high-level set of national outcome goals covering the responsibilities of the NHS, against which the Secretary of State for Health will hold the Board to account. It is available to support NHS organisations in delivering improved outcomes from April 2011, with full implementation from April 2012.
- 3.5 There are five domains in *Transparency in outcomes: NHS Outcomes Framework 2011/12*:
- preventing people from dying prematurely;
  - enhancing quality of life for people with long-term conditions;

- helping people to recover from episodes of ill health or following injury;
- ensuring people have a positive experience of care; and
- treating and caring for people in a safe environment and protecting them from avoidable harm.

3.6 Cancer is identified in domain 1 as a specific improvement area for preventing people from dying prematurely, given that international evidence suggests there is scope for improvement.

3.7 Measures included as outcome goals within the outcomes frameworks are necessarily high level. The NHS Commissioning Board will set out more detailed measures as part of its Commissioning Outcomes Framework, which it will use to hold GP consortia to account for securing improvements in outcomes. It is not appropriate to pre-empt the Board decisions by suggesting how they may wish to do this in relation to cancer outcomes, but Box 1 sets out some examples of possible indicators and data sources.

**Box 1 – *Transparency in outcomes: NHS Outcomes Framework 2011/12 and cancer***

Improving cancer care will be relevant to all five domains of *Transparency in outcomes: NHS Outcomes Framework 2011/12*:

1. Preventing people from dying prematurely (cancer is identified as a specific improvement area)

**One-year and five-year cancer survival rates**

Other relevant indicators:

- mortality from cancer by age
- number of patients with cancers diagnosed as an emergency admission or attendance
- patients with cancer diagnosed at stage 1 and 2, as a proportion of cancers diagnosed
- the inequality gaps between different groups and areas
- active treatment rates

## 2. Enhancing quality of life for people with long-term conditions

Possible indicators:

- cancer Patient Reported Outcome Measures (PROMs) and surveys of cancer survivors
- proportion of working age cancer survivors who are able to work and are in work
- proportion of children or young people cancer survivors in education or employment
- proportion of cancer survivors able to live independently

## 3. Helping people to recover from episodes of ill health or following injury

Possible indicators:

- recovery after cancer surgery
- ill health associated with cancer treatment
- proportion of people reporting unmet psychological support needs following cancer treatment

## 4. Ensuring people have a positive experience of care

Possible indicators:

- annual cancer patient experience surveys to monitor the experience of cancer patients
- an index based on the overall experience of patients for reporting at Trust level
- surveys of bereaved relatives as a proxy for patients to assess the quality of care given at the end of life

## 5. Treating and caring for people in a safe environment and protecting them from avoidable harm

Possible indicators:

- 90-day mortality following completion of radical or adjuvant radiotherapy
- 30-day mortality following palliative radiotherapy
- wrong route chemotherapy
- 30-day mortality following chemotherapy
- death or severe disability following surgery
- case mix adjusted 30-day mortality following surgery

### 3.8 However, given that:

- one of the high level indicators is to relate to improvements in survival;
- there is a time lag in collecting this data and so the NHS Commissioning Board will need proxy indicators to assess the NHS's progress;
- some proxy indicators need action now in order to ensure that the data are available if the Board wishes to have such indicators; and
- the information will be very useful for commissioners, providers and patients in assessing progress towards the required survival rate improvements,

DH will take action now to move forward on a range of new data collections/analyses. These relate to:

- the proportion of cancers diagnosed at Stages 1 and 2;
- the proportion of cancers diagnosed through emergency routes;

(both of these are evidence based in relation to being proxies for survival rates); and

- GP usage of diagnostic tests.

### 3.9 In line with the first item, the Operating Framework for the NHS in England 2011/12<sup>17</sup> has made it clear that providers are expected to include staging data in the information they feed to cancer registries.

### 3.10 Turning to the level of ambition for cancer survival rate improvements, the information from the International Cancer Benchmarking Project (see 1.12) shows that England has poorer survival rates for colorectal,

lung, breast and ovarian cancer compared with other (non-UK) countries in the study. Australia, Canada and Sweden had the best survival. Much of the difference in 5-year survival for each cancer can be attributed to poor one-year survival in England. Although the survival gap has narrowed for breast and ovarian cancer, it has remained broadly similar for colorectal and lung cancer.

- 3.11 Our aspiration is that England should achieve cancer outcomes which are comparable with the best in the world. However, the changes required to deliver on this aspiration are complex:
- it takes time to bring about change, particularly the cultural change required so that people are encouraged to present earlier to their GP when they have signs and symptoms and for the GP to swiftly refer them on to secondary care;
  - service developments, such as introducing new screening programmes on the advice of the UK National Screening Committee (UK NSC) or developing new diagnostic services, must be planned and introduced in a sustainable and safe manner;
  - the evidence base for what works in delivering earlier diagnosis is still being developed;
  - there is still more work to do through the ICBP to identify the reasons for better survival rates in other countries; and
  - delivering improved survival rates has cost implications.
- 3.12 It is mainly through earlier diagnosis where these lives will be saved (see chapter 4). The Impact Assessment for this Strategy shows, on the basis of modelling work, how many lives per year we think we can save with the additional funding which the Government is making available in this Spending Review. We believe that, by 2014/15, 5,000 additional lives can be saved each year. It is now for the NHS, working with PHE, to deliver this ambition. Earlier diagnosis should therefore be a priority for NHS action now and this will be included in the mandate for the NHS Commissioning Board (working with PHE) for the future.
- 3.13 Chapter 5 sets out planned improvements in outcomes relevant to the long-term conditions and patient experience domains and chapter 6 sets out planned improvements in outcomes relevant to the safety, helping people to recover from episodes of ill health and preventing people dying prematurely domains.

### Waiting times standards

- 3.14 In the past, the main focus of performance management in relation to cancer services has been in relation to waiting times standards. In summer 2010 the National Cancer Director was commissioned to review the cancer waiting time standards. The aim of this review was to determine whether these standards should be retained and what, if any, changes were required.
- 3.15 The outcome of the review confirmed that, overall, cancer waiting time standards should be retained. Shorter waiting times can help to ease patient anxiety and, at best, can lead to earlier diagnosis, quicker treatment, a lower risk of complications, an enhanced patient experience and improved cancer outcomes. The current cancer waiting times standards will therefore be retained. As set out in the Operating Framework for the NHS in England 2011/12, commissioners will need to continue to reflect this in the contracts that they agree with providers. It will in time be for the NHS Commissioning Board to discuss with the Secretary of State whether more refined measures should be adopted, but this will be done with the clear expectation that this will only be sanctioned if new proposals improve access for patients. The report of the cancer waiting times review is being published separately and the executive summary of that report is attached at Annex C.

### Social Care Outcomes Framework

- 3.16 The consultation document *Transparency in outcomes: a framework for adult social care*<sup>18</sup> aims to ensure the best outcomes are achieved for those needing social care, their families and carers, and the wider local community, by improving the quality of services and supporting transparent local accountability. The consultation proposes using a set of outcome measures for this purpose, including a number of suggested measures which will have particular relevance for cancer patients and their carers. As the number of people living with cancer increases, so it will become ever more important to ensure the quality of life for those with cancer is maximised. It will also be critical to support a personalised approach to living with cancer; equipping cancer patients, their families and carers, with the information they need in formats and languages they understand to make choices about their ongoing care and support. The new approach to transparency, quality and outcomes in adult social care will help achieve this.

## Improving public health cancer outcomes

3.17 *Healthy Lives, Healthy People* sets a clear vision for public health and disease prevention focused on improving the healthy life expectancy of the population and improving the health of the poorest, fastest. It introduces three key shifts:

- public health will be locally led, with local, ring-fenced budgets and powers;
- public health will be unified, focused on outcomes, and will do what works; and
- responsibility and partnership will be strengthened at every level.

3.18 To drive improvements in public health, proposals to develop a Public Health Outcomes Framework are currently out to consultation. *Healthy Lives, Healthy People: Transparency in Outcomes* sets proposed high level ambitions for health improvement, protection and the prevention of ill health. It will be for those working at local level to decide how best to deliver improvements against these high-level outcomes. A number of key indicators spanning several of the proposed domains will drive efforts to prevent cancers, improve screening participation and support earlier diagnosis. The proposed relevant indicators are:

- population vaccination coverage (for each of the national vaccination programmes across the life course);
- prevalence of healthy weight in 4-5 and 10-11 year olds;
- prevalence of healthy weight in adults;
- smoking prevalence in adults (over 18)
- rate of hospital admissions per 100,000 for alcohol related harm;
- percentage of adults meeting the recommended guidelines on physical activity (5 x 30 minutes per week);
- screening participation;
- patients with cancer diagnosed at stage 1 and 2 as a proportion of cancers diagnosed; and
- cancer mortality in persons less than 75 years of age.

3.19 To improve cancer outcomes the NHS and PHE will work together closely, offering integrated advice and care to the public and patients. There are clear areas of shared accountability between the outcomes frameworks to recognise the responsibilities of the NHS and PHE in delivering improvements. Whilst *Transparency in Outcomes: NHS Outcomes Framework 2011/12* has cancer survival as an improvement area, it is proposed in *Healthy Lives, Healthy People: Transparency in Outcomes* that cancer mortality should be an improvement area for PHE, as this covers improvements in prevention as well as in diagnosis and treatment.

## 4. Improving outcomes for cancer patients: prevention and earlier diagnosis

### Introduction

- 4.1 To achieve our ambition that cancer mortality and survival rates should match the best, it will be essential to prevent more cancers developing in the first place and to ensure they are diagnosed while the cancer is at an earlier stage. Tackling inequalities will be fundamental to this.

### Public Health England (PHE)

- 4.2 A range of services relevant to cancer will in future be the responsibility of PHE, including:
- public health intelligence;
  - primary prevention interventions;
  - human papilloma virus (HPV) vaccination services;
  - screening programmes, including screening quality assurance (QA);
  - targeted campaigns to raise public awareness of symptoms and to encourage early presentation; and
  - recording and analysis of cancer-relevant data via the cancer registries.
- 4.3 Subject to consultation on *Healthy Lives, Healthy People* and associated consultation documents, PHE will publish evidence on what works in cancer prevention, awareness and screening and report public health data, including outcomes. The cancer registries will be part of PHE. The information they provide about cancer registrations is very important for the planning and commissioning of services. With the development of electronic systems, it is now possible to get this data much more quickly than was feasible in the past. Some registries have made very significant strides in improving the completeness and speed of production of data, and DH will ensure that, during 2011/12, all registries work towards meeting the standards of the best.

- 4.4 As set out in Chapter 3, *Healthy Lives, Healthy People: Transparency in Outcomes* proposes a number of cancer relevant outcomes indicators to help prevent cancers and diagnose them earlier. The framework will work across public services at all levels of responsibility – national to local. It will also link with *Transparency in Outcomes: NHS Outcomes Framework 2011/12* and the forthcoming Social Care Outcomes Framework to ensure an integrated approach.
- 4.5 The UK National Screening Committee (UK NSC) will continue to advise Ministers on all aspects of new screening programmes and aspects of existing ones. PHE will set national policy, pilot and evaluate new cancer screening programmes or extensions to existing ones and run quality assurance programmes. The NHS Commissioning Board will commission screening programmes on behalf of PHE to agreed levels of service.
- 4.6 PHE's cancer symptom awareness campaigns will also be commissioned at the national level, sometimes in conjunction with the NHS Commissioning Board. At the local level, Directors of Public Health working in local authorities will wish to drive cancer prevention and awareness through health improvement strategies. They will work closely with the local NHS to diagnose cancers earlier. The role of health and wellbeing boards will be significantly strengthened, and joint working will be enhanced through a new responsibility to develop a "joint health and wellbeing strategy" spanning the NHS, social care, public health and potentially other local services. Subject to consultation, local authorities will be held to account, jointly with the NHS, for delivering earlier diagnosis of cancer through the Outcomes Frameworks.

## Prevention

- 4.7 Our lifestyle choices affect our risk of developing cancer. Up to half of all cancers could be prevented by changes in lifestyle behaviours. *Healthy Lives, Healthy People* recognises the need for a new approach to improving the public's health, which will support cancer prevention efforts.
- 4.8 If we are to tackle the health problems caused by smoking, poor diet, obesity, alcohol misuse and lack of exercise effectively, we need a whole-society approach that supports and enables people to change their behaviour. We need to work in partnership, across all parts of society, to create an environment that supports the public to make healthy choices, by making the healthier choice the easier choice.

- 4.9 When it is launched early in 2011, the Public Health Responsibility Deal will set out the actions that industry, the voluntary sector, NGOs and local government will take to help people make healthier choices. At a local level, Directors of Public Health based in local authorities will provide strategic leadership on public health across the local health economy along with a public health budget that is ring-fenced to ensure it is used as it should be: to tackle preventable causes of ill-health.
- 4.10 Smoking is the major preventable risk factor for cancer. Dissuading people from starting to smoke and helping people to quit remain critical. We will publish a tobacco control plan which will set out more detail on how the Coalition Government proposes to reduce smoking prevalence.
- 4.11 Those who are overweight or obese are more likely to develop cancer and more likely to die from cancer. As stated in *Healthy Lives, Healthy People*, we will be publishing a document on obesity in Spring 2011. This will set out the Government's commitment to tackling obesity and the role that key partners can play. We will continue to support families to make informed choices about their diet and their levels of physical activity, with Change4Life continuing to play a key role.
- 4.12 We will also continue to support skin cancer prevention campaigns to raise awareness of protective behaviours. NICE guidance on the prevention of skin cancer is in development and will be published in 2011. It should inform local interventions as well as national campaigns. The Sunbeds (Regulation) Act, which comes into force in the spring of 2011, makes it an offence to allow someone under 18 years to use a sunbed on commercial premises.
- 4.13 Promoting good health via workplace initiatives is an important strand of the life course approach. Our Big Society approach to improving cancer outcomes details how we will support workplace prevention efforts in partnership with others.
- 4.14 It is also critical to protect people from cancer-related workplace risks. Research undertaken by Imperial College London (ICL) for the Health and Safety Executive (HSE) estimates that over 8,000 cancer deaths per year are due to occupational exposures in Great Britain. HSE's plan for 2010/11 included identifying where the highest risks of such diseases exist in today's world of work and then taking a range of approaches to reduce exposure to causative agents. These include working with influential stakeholders in those sectors to support them to raise awareness and encourage behaviour change, and using the inspection and enforcement capability to address poor performing businesses.

- 4.15 The International Agency for Research on Cancer has classified shift work as “probably carcinogenic” for humans, and the ICL research has also suggested a link, estimating around 500 breast cancer deaths per year could be due to shift work. The HSE has commissioned further major research to explore the potential association of shift work with breast cancer, other cancers and other major diseases. The HSE has also commissioned a number of research projects relating to asbestos.
- 4.16 A recent study has shown that taking low dose aspirin for several years may reduce mortality from cancer by 20%.<sup>19</sup> DH will work with Cancer Research UK during 2011 to review these findings and to consider what further work is needed in this area in order to provide appropriate advice to the public.

## Secondary prevention

- 4.17 There is increasing evidence that lifestyle changes can reduce the risk of recurrence for cancer survivors, the impact of side effects of treatment and the burden of cancer survivors on the NHS and the benefits system. The clearest evidence for the impact on survival of lifestyle interventions following cancer diagnosis is for physical activity for survivors of breast cancer, colorectal cancer and prostate cancer.
- 4.18 The NHS will use the generic long-term conditions model of care and support to promote healthy lifestyles for rehabilitation from cancer and to encourage secondary prevention. In particular, *Let's Get Moving*, a brief intervention model to promote physical activity in primary care, can be used to help patients set and monitor their own physical activity goals, for example as part of the six-month patient follow-up. The new specialism of Sport and Exercise Medicine and exercise referral can also benefit patients who need help and support to exercise safely.
- 4.19 An example of how increasing knowledge of the importance of secondary prevention is being translated into practical support for patients is the Bournemouth After Cancer Survivorship Programme (BACSUP). This programme is a person centred, physical activity referral programme designed and provided to improve the potential for patients living with cancer to lead as healthy and active a life as possible, for as long as possible. To date, 200 referred participants and 52 “buddies” have benefited from one to one personalised guidance and goal setting, health and fitness screening and a wide range of community based activity opportunities, including fitness classes, health walks, swimming lessons and dance classes. The programme has demonstrated wide-ranging improvements in many

of the common problems facing cancer survivors, as well as many other significant benefits that improve survivorship through enhanced health, wellbeing and quality of life.

- 4.20 The evidence base on secondary prevention is still emerging. In order to support commissioners, and where evidence exists, standards on secondary prevention will be included in relevant commissioning packs and may be considered by NICE for inclusion in Quality Standards.

### Screening

- 4.21 Cancer screening remains an important way to detect cancer early, and in some cases, such as cervical screening, prevent cancers. Over 5% of all cancers are currently diagnosed via screening, but this is set to rise as the extensions to the breast and bowel screening programmes progress. Around a third of breast cancers are now diagnosed through screening, but we recognise that some groups and communities are not accessing these services.
- 4.22 Subject to the consultation on *Healthy Lives, Healthy People*, PHE will have responsibility for national elements of the cancer screening programmes, including QA. We will take the opportunity to bring together the screening QA services and make sure that they all deliver at the level of the best. PHE will fund the NHS Commissioning Board annually to commission local elements of screening programmes on behalf of PHE. During 2011/12, DH will explore the development of a tariff for breast cancer screening and bowel cancer screening to encourage providers to improve participation rates, and reduce variation between different parts of the country and among different groups as well as to facilitate patient choice.

### HPV vaccination and testing

- 4.23 A national HPV immunisation programme began roll out in 2008, for school age girls aged 12 to 13 and a catch-up programme up to 18 years. Uptake has been consistently very high, with 80% of 12-13 year-old girls in Year 8 having received three doses of the vaccine in 2008/09. In the third year of the programme, by November 2010, 76.9% of girls aged 12 to 13 years had received their first dose of vaccine compared to 72.8% by November 2008/09 and 64.9% by November 2009/10.

### Cervical screening

- 4.24 HPV testing as triage (sorting) for women with mild or borderline cervical screening test results has been piloted and shown to be effective. Women with mild or borderline results are tested for HPV and if negative are

returned to the routine screening programme. Women who are HPV positive are referred to colposcopy. HPV testing can also be used to test whether women who have had cervical abnormalities treated have been cured and this has been shown to be effective. The Government will roll out HPV testing across England as triage for women with mild or borderline cervical screening test results and as a test of cure for treated women. The Operating Framework for the NHS in England 2011/12 states that commissioners should work with their local services and NHS Cancer Screening Programmes to implement HPV testing as triage for women with mild or borderline results, leading to a more patient centred service and major cost savings.

- 4.25 The Operating Framework for the NHS in England 2011/12 also states that commissioners should ensure that cervical screening results continue to be received within 14 days. As at November 2010, 81% of women were receiving their results within 14 days. As recommended by the Advisory Committee on Cervical Screening (ACCS), the threshold for achieving this has been set at 98%. PHE will continue to reflect the advice of the ACCS in commissioning the service. By taking a complete screening pathway approach, achieving a 14 day turnaround time has also been shown to be cost saving, with an average £100,000 saved per unit per year. Some cancer networks are using this in their local Quality Innovation Productivity Prevention (QIPP) programmes.

### Breast cancer screening

- 4.26 The NHS Breast Screening Programme (NHS BSP) is currently being extended to women aged 47-49 and 71-73. The Operating Framework for the NHS in England 2011/12 states that commissioners should ensure that all screening services continue to take part in the breast screening age extension randomisation project, either screening women aged 47-49 or 71-73, depending on the randomisation protocol. As at November 2010, 17 out of 81 local programmes had implemented the extension randomisation.
- 4.27 The randomisation project, led by researchers at the University of Oxford, will give directly comparable mortality data on the effectiveness of screening including the benefits and harms in these populations. The results of the project will be internationally important to show whether screening in the extended age ranges is effective or not. That is why the Government intends to run the randomisation of the breast screening age extension over two three-year screening rounds rather than one. This will not only allow us to gather world class data on the effectiveness of screening these age groups, but will save £12 million per year. Ethical approval has already been

granted to run the project over two rounds. Full roll-out to women aged 47-49 and 71-73 is therefore expected to be completed after 2016.

- 4.28 In combination with the age extension, local breast screening programmes are replacing their current film systems with digital systems (direct digital mammography). At the end of 2010, over 80% of screening programmes had at least one direct digital x-ray set and nearly 30% will be fully digital. We have advised programmes to move to direct digital as quickly as possible as the independent Advisory Committee on Breast Cancer Screening (ACBCS) has said that running both film and digital systems together is inefficient.
- 4.29 Under the guidance of the ACBCS, the information leaflet sent out with all invitations for breast screening has been revised to take account of the latest evidence on breast cancer screening and informed choice. The ACBCS is also developing a practical guideline for the NHS on the surveillance of women deemed to be at a higher risk of breast cancer. Following successful pilots, the NHS Breast Cancer Screening Programmes is now in a position to begin managing the surveillance of high risk women across England.

### **Bowel cancer screening**

- 4.30 Full roll-out of the original NHS Bowel Cancer Screening Programme for 60-69 year olds (using the Faecal Occult Blood test – FOBt) was completed in July 2010, with 100% coverage of PCT populations. Between July 2006 when the Programme began and December 2010, over 8 million kits had been sent out and nearly 5 million returned. 7,065 cancers had been detected, and over 40,000 patients had undergone polyp removal. Over 100,000 men and women aged 70 or over had self-referred into the programme.
- 4.31 The NHS BCSP is currently being extended to men and women aged 70 to their 75th birthday. The Operating Framework for the NHS in England 2011/12 states that commissioners should ensure that all local screening centres maintain the two-year screening round for bowel cancer. The extensions begun in 2010/11 should continue and be maintained for 2011/12. Those centres whose end of original round in 2011/12 should implement extension on completion of the original round. Those whose two-year screening round falls beyond 2011/12 should prepare to expand on completion of the original round. As at November 2010, 29 of the 58 local screening centres had implemented the extension. In addition, NHS Cancer Screening Programmes will be looking at how the more accurate and easier to use immunochemical FOBt can be introduced into the programme potentially to increase uptake and to provide more accurate results.

- 4.32 Flexible sigmoidoscopy (FS) is an alternative and complementary bowel screening methodology to Faecal Occult Blood (FOB) testing. A randomised controlled trial funded by Cancer Research UK, the Medical Research Council and NHS R&D took place in 14 UK centres between 1994 and 2010 to evaluate screening for bowel cancer using FS. It concluded that FS is a safe and practical test and, when offered only once between ages 55 and 64 years, confers a substantial and long lasting benefit. Based on trial figures, experts estimate the programme would prevent around 3,000 cancers every year.
- 4.33 The DH has committed to invest £60 million over the next four years to incorporate FS into the current bowel screening programme subject to UK NSC approval. Pilots will begin during 2011/12 with the aim of achieving 30% coverage by the end of 2013/14 and 60% by the end of 2014/15. It is envisaged that full roll out will be achieved in 2016. Subject to the consultation on *Healthy Lives, Healthy People*, PHE will retain responsibility for the commissioning of the FS programme during piloting and roll-out, and will fund the NHS Commissioning Board to commission local elements of the programme from 2016/17 onwards.

### Improving access to the cancer screening programmes

- 4.34 To maximise the benefits from the screening programmes, we need to empower the greatest number possible from all groups and communities (particularly those under-represented and excluded) to make an informed choice to participate in cancer screening. We are therefore working with the Cabinet Office Behavioural Insight Unit to consider options for promoting informed choice. In addition, we are planning to use the two regional campaigns on bowel cancer symptoms as a lever for raising awareness of the screening programme in those areas – and evaluation of those campaigns will help us assess appropriate next steps.

### Screening for other cancers

- 4.35 The NHS Constitution commits the Government to provide screening programmes as recommended by the UK NSC.
- 4.36 The UK NSC reviewed the evidence for prostate cancer screening between March 2009 and June 2010. The UK NSC concluded that men should not be invited for Prostate Specific Antigen (PSA) testing because the risks of over-diagnosis far outweighed any potential reduction in mortality. The UK NSC policy will be reviewed in three years time, or earlier if major new research evidence becomes available. Following public and stakeholder consultation the UK NSC recommended that additional modelling of high risk groups is conducted and further education of GPs through the

Prostate Cancer Risk Management Programme (PCRMP) should also be taken forward. To ensure that men are well informed about the signs and symptoms of prostate cancer and empowered to request a PSA test if they want one, the UK NSC has asked the Prostate Cancer Advisory Group to explore options for making the PCRMP information more accessible to men.

- 4.37 The cancer research community remains committed to investigating screening approaches in other cancers and several research programmes are ongoing. The control arm of the ProtecT trial (Prostate testing for cancer and treatment) and the UKTOCs trial (UK collaborative trial for ovarian cancer screening) both are due to finish around 2015, and their findings will be considered by the UK NSC. The National Institute for Health Research (NIHR) Health Technology Appraisal (HTA) Programme has funded a feasibility study into lung cancer screening using spiral Computed Tomography (CT). Plans for a subsequent pilot study have now been agreed. There are also a number of international trials ongoing, which we are monitoring closely. Preliminary findings from the National Lung Cancer Screening Trial in the US have recently been announced, showing a reduction in lung cancer mortality of 20% in people undergoing spiral CT.<sup>20</sup> The full study results are expected next year.

### Early diagnosis: what PHE will deliver

- 4.38 As outlined in Chapter 1, later diagnosis in England is a major explanation for poorer survival rates and, if patients were diagnosed at the same earlier stage as they are in other countries, up to 10,000 deaths could be avoided every year. We know that 95% of patients present with symptoms and that nearly a quarter of all cancers are diagnosed through an emergency route. The scale of the challenge is clear. In order to improve early diagnosis, we need to encourage people to recognise the symptoms and signs of cancer and seek advice from their doctor as soon as possible. We also need doctors to recognise these symptoms and (if appropriate) refer people urgently for specialist care.
- 4.39 We need to increase awareness of the symptoms and signs of cancer among millions of people as well as encouraging a culture shift so that people visit their doctor promptly when they do suspect cancer. We need particularly to target the over 50s and recognise that lack of symptom awareness applies to affluent and disadvantaged groups but is more acute in disadvantaged groups.
- 4.40 Significant work has already been undertaken through the National Awareness and Early Diagnosis Initiative (NAEDI) which is being jointly led by DH and Cancer Research UK to test relevant local interventions.

For example, the Doncaster Cough Campaign for lung cancer achieved an increase in the number of people seeing their GP and an increase in patients diagnosed at an earlier stage of lung cancer – from 11% to 19%.<sup>21</sup>

- 4.41 In 2010 DH began a £10.75m local and national “signs and symptoms” campaign. The campaign consists of 59 local campaigns focusing on the three cancers accounting for the greatest number of deaths – breast, bowel and lung cancer. A range of approaches are being taken across different projects but all will aim to raise public awareness of the symptoms of cancer, changing public behaviour to promote early presentation to primary care and on encouraging primary care to respond appropriately. In two regions, the DH will also be trialling centrally led campaign activity to raise awareness of bowel cancer symptoms and to encourage early presentation. Subject to evaluation, DH will roll out the campaign across the country.
- 4.42 To amplify the early detection message, DH is seeking to engage a number of public sector and commercial partners in the two pilot regions. On the public sector side, DH is encouraging organisations including local authorities, libraries, police authorities, local fire services, Citizens Advice Bureaux and the Territorial Army to display posters and leaflets and include information in their newsletters and on their intranets to promote the campaign to their workforce, as well as to the public.
- 4.43 DH is liaising with a number of commercial partners such as Kimberly-Clark who will be communicating messages to their employees in a number of their manufacturing sites. We are also targeting pharmacists through the Royal Pharmaceutical Society, the Company Chemists Association and the National Pharmacist Association.
- 4.44 Other health professionals have important roles to play in encouraging the prevention and early detection of some cancers. PHE at a national level will therefore wish to work to engage relevant health professionals in tackling late diagnosis. Local authorities working through local health and well-being boards will also wish to promote symptom awareness in their communities and engage health professionals at a local level to prioritise the earlier diagnosis of cancer.

## Earlier diagnosis – the NHS role

### Promotion of screening and symptom awareness by GPs

- 4.45 Although overall responsibility for promoting screening and symptom awareness lies with PHE, this is a standard and very important role for GPs as well. If they take opportunities to encourage their patients to think about the importance of screening or to remind them to think about symptom

awareness, this can have a very significant impact on patient behaviour. Through a variety of means we will seek to encourage GPs to raise these issues with their patients.

### Supporting GPs to assess patients effectively

- 4.46 GPs see only around 8 or 9 new patients with cancer each year. However, they see many more presenting with symptoms that could be cancer. And those symptoms are generally symptoms of many other diseases as well. This therefore makes it difficult for GPs to assess when it is appropriate to refer patients on to secondary care for investigation.
- 4.47 There is a range of support available, for example NICE referral guidelines, and DH has funded a number of initiatives to support GPs, such as an audit of cancer diagnoses within primary care. In the areas where we are funding awareness raising campaigns, local GPs are involved in the development of the projects. For the regional pilots of the bowel cancer symptom campaign, GPs will have a centrally developed resource pack to ensure that they are fully aware that the symptoms could be bowel cancer and may require referral on to secondary care.
- 4.48 And more work is underway, for example:
- a risk assessment tool for GPs has been developed and is about to be tested in a number of pilot areas;
  - we are working with the medical defence organisations to use clinical negligence claims data (one of the organisations has told us that in 2009 19% of their claims related to the diagnosis, investigation or treatment of a cancer patient) where support may best be targeted;
  - we are looking at how decision support tools, risk assessment, safety netting practices and audit can be integrated into GP training, appraisal and revalidation;
  - we are analysing data from the national cancer patient experience survey to identify patient groups who may not be quickly identified by GPs and those who are not seen by a GP before diagnosis; and
  - we have commissioned retrospective and prospective studies of young women with cervical cancer.
- 4.49 We have talked to many GPs as part of the development of this Strategy, and they have raised a number of important issues for us to take forward. For example, many have said that it would be helpful to have closer relationships with their colleagues in secondary care as a way of making good judgements about which cases to refer on.

## Access to diagnostic tests

- 4.50 GPs need easy access to the right diagnostic tests to help them to diagnose or exclude cancer earlier. We are committing additional funding over the next four years to enable GPs to have better access to selected diagnostic tests, along with funding for the additional costs of tests and treatment in secondary care. The Operating Framework for the NHS in England 2011/12 asked commissioners and providers to take action to begin to deliver this.
- 4.51 Following advice from the Cancer Diagnostics Advisory Board, DH's view is that GPs need to be able directly to access the following tests for patients for whom the two week urgent referral pathway is not appropriate, but symptoms require further investigation:
- chest x ray: to support the diagnosis of lung cancer;
  - non-obstetric ultrasound: to support the diagnosis of ovarian and other abdomino-pelvic cancers;
  - flexible-sigmoidoscopy/colonoscopy: to support the diagnosis of bowel cancer; and
  - Magnetic Resonance Imaging (MRI) brain: to support the diagnosis of brain cancer.
- 4.52 All GPs have access to chest x-rays and variable access to non-obstetric ultrasound, but there is little primary care access to the other tests. The additional funding will enable expansion of diagnostic testing to allow for more tests, so that more people can be checked earlier when they have presented with the relevant symptoms. Other tests, such as Computed Tomography (CT) scanning, are not currently considered appropriate for direct GP access, as they are not a first test that primary care requires access to.
- 4.53 The Impact Assessment contains full details of:
- what this additional funding could purchase in terms of extra tests;
  - the extra costs of people being tested in secondary care and treated earlier because of earlier diagnosis; and
  - the lives that can be saved by these earlier diagnoses.
- 4.54 It will be the role of GP consortia to commission the additional direct access tests. Although the focus of this additional funding is on using diagnostic tests as a way of excluding or confirming cancer earlier, it may well be that GPs choose other approaches to delivering earlier diagnosis, eg increased

use of the urgent referral pathway. What matters is that earlier diagnosis is delivered, and that survival rates improve. The funding is available to deliver the improved survival rates, and that is what the NHS will be held to account for delivering.

- 4.55 We will work to ensure that tariffs incentivise quick and where appropriate direct access to diagnostics.
- 4.56 DH will also ensure that data is routinely collected about GP usage of these tests, so that GPs can benchmark their use of them. This data will be published, alongside data about GPs' usage of the two-week urgent referral pathway, as there will be a balance between how GPs use these two approaches to cancer diagnosis.
- 4.57 Working with the Cancer Diagnostics Advisory Board, DH will ensure that appropriate criteria for direct access to diagnostic tests are drawn up in 2011.

### Rarer cancers

- 4.58 For GPs, spotting the signs and symptoms of rarer forms of cancer can be particularly challenging, as they may only see one or two instances of the cancer in question in their career. It is, however, clear that more needs to be done to raise awareness of the signs and symptoms of rarer cancers and to improve the pathway to diagnosis for people with rarer cancers. A recent survey<sup>22</sup> by the Rarer Cancers Foundation of nearly 400 patients found that nearly one third of respondents had been reassured by their GP and not asked to return when they had first presented with symptoms. Perhaps unsurprisingly, a similar proportion of respondents rated their experience of the pre-diagnosis phase of their care as poor or very poor. Of those who responded to the survey, more than one quarter reported that their cancer was diagnosed at an advanced stage.
- 4.59 Providing high quality decision aids and promoting early referral to secondary care will be central to our efforts to improve the diagnosis of rarer forms of cancer, as well as more common tumours. Through NAEDI, in 2011/12 DH will also work with charities which represent patients with rarer forms of cancer to assess what more can be done to encourage appropriate referrals and earlier diagnosis of rarer cancers.

### Benchmarking performance

- 4.60 As explained in chapter 2, we will ensure that GPs have the data they need to benchmark their performance in relation to the diagnosis of cancer.

# 5. Improving outcomes for cancer patients: quality of life and patient experience

## Introduction

- 5.1 There are now about 1.8 million people living in England who have had a cancer diagnosis. By 2030 it is anticipated that there will be 3 million people in England living with and beyond cancer. Nearly two thirds of cancer survivors are over 65 years old<sup>23</sup> and, while incidence of cancer for children and young people is low, high overall survival rates mean there are growing numbers of children, young people and adults who have been treated for childhood cancer.
- 5.2 People living with and beyond cancer often have specific support needs which, if left unmet, can damage their long-term prognosis and ability to lead an active and healthy life. These needs can include information about treatment and care options, psychological support, access to advice on financial assistance and support in self-managing their condition. Carers also play a vital role in supporting people with cancer and it is important that their needs for information, advice and support are addressed. Addressing all these needs is central to the National Cancer Survivorship Initiative (NCSI), which is coordinating efforts to improve the quality of services available to people affected by cancer.
- 5.3 Although there have been significant improvements in support for people living with and beyond cancer, more needs to be done so that cancer survivors have the care and support they need to live as healthy a life as possible, for as long as possible. We want to see improvements in the outcomes which are particularly relevant for people living with and beyond cancer, such as:
- reducing ill health associated with cancer treatment;
  - reducing risks of recurrent cancer;
  - reducing the proportion of people who report unmet physical or psychological support needs following cancer treatment;
  - increasing the proportion of cancer survivors of working age who are able to work who are in work;

- increasing the proportion of children or young people survivors who are in education or employment; and
- increasing the proportion of cancer survivors who are able to live independently.

### Advanced communication skills

- 5.4 Written information is an adjunct, not a substitute, for high quality verbal communication. The way healthcare professionals communicate with those using the health service profoundly affects the experience of care for patients. Good communication can facilitate early diagnosis, improve self-management, reduce emergency admissions, reduce inequalities in access and provision of care, and support people to return to as normal a life as possible following cancer treatment. It is also critical to empowering patients to exercise informed choice. Poor communication has a direct cost impact as inadequate communication is at the heart of many NHS complaints and litigation.
- 5.5 Good communication skills are also important in communicating with carers and family members. Family members too have choices and assumptions should not be made about their ability and willingness to care. The knowledge and experience of those who undertake caring responsibilities should be recognised and valued – they should be listened to and involved in care planning.
- 5.6 Yet effective communication with people with cancer and their families can be a difficult process, often involving providing unwelcome news or supporting patients and carers in making extremely difficult decisions. Helping clinicians to develop their communication skills and processes is therefore important.
- 5.7 The National Cancer Action Team (NCAT) currently provide a course to allow clinicians to learn through role play and constructive feedback about how their communication style impacts on patients. Commissioners and providers will need to consider how best to ensure that their clinicians have the necessary skills to communicate effectively with patients. In 2011/12, while they are developing their arrangements, central funding of this training will continue.

## Cancer patient experience

- 5.8 The 2010 cancer patient experience survey shows that, in many areas, patient experience is improving. This is very welcome. The survey also highlights areas where further progress is needed. (See Annex B for further information.) For example, compared with previous surveys, fewer people understood doctors' and nurses' answers all or most of the time and fewer people completely understood an explanation of their diagnosis. A significant proportion of patients felt there were not always enough nurses on duty. There were two other very important findings. Patients rated the support offered by clinical nurse specialists (CNSs) highly and those who received the support of a CNS reported having a better patient experience.
- 5.9 The 2010 survey built on previous surveys undertaken in 2000 and 2004. Although these surveys were important in enabling national benchmarking, feedback suggests they had little impact in driving improvements in the quality of services locally. In order to address this, provider-level analyses of survey findings are being developed and published so that commissioners are supported in directly incentivising improvements in cancer patient experience, eg through including ambitious improvement goals in locally agreed Commissioning for Quality and Innovation (CQUIN) schemes. DH is committed to repeating the cancer patient experience survey.

## One to one support

- 5.10 There is growing evidence that coordinated care, such as that provided by CNSs, can deliver better outcomes for patients. While the 2010 cancer patient experience survey suggests that the majority of people going through cancer treatment have access to the support of a named CNS, and that their experience of their treatment and support is significantly better than that of other patients, we know that access to such support varies. There are some tumour types where there are too few CNSs and people with metastatic cancer have less access to support from CNSs than patients experiencing their primary treatment.
- 5.11 During 2010 DH worked with Macmillan Cancer Support to understand the role and impact of one to one support for cancer patients and the cost effectiveness of providing such support for cancer patients at all stages of the cancer pathway. In December 2010 we published a modelling report by Frontier Economics<sup>24</sup> which sets out the costs and benefits of one to one support which shows that, in many scenarios, the costs of additional support roles are likely to be outweighed by the savings that can be achieved. These savings include reductions in emergency bed days,

reductions in routine follow-up appointments, and reductions in GP visits. This is good news in the current climate.

- 5.12 Macmillan Cancer Support is committed to investing £300 million over the next 7-10 years which will support the NHS to create up to 2,700 additional one to one support posts. This money will fund CNSs and care co-ordinators, to support patients in a seamless way during treatment and in aftercare. Some new posts will be hospital based and others will work in the patient's home community. This investment will enable the NHS to achieve whole systems improvements across the cancer pathway. It will include workforce and process re-design, learning and development, and consultancy. Where commissioners are committed to developing new models of provision, the NHS will be able to provide one to one support with initial investment from Macmillan and generate quality benefits and savings in the longer term.
- 5.13 CLIC Sargent is also committed to continuing to pump prime a range of CNS roles for the 0-18 year age group and from 2011/14 additional funds will be invested in CNS posts to test, develop and evaluate the key-worker role. This will provide innovative approaches to the delivery of support for children with cancer.
- 5.14 We will build on the Frontier Economics report to provide further evidence to support the NHS to develop new one to one support posts. We will highlight issues that service providers and commissioners need to consider as part of workforce planning. Given the very high value placed on CNSs by patients, and the improved outcomes for patients who have a CNS, we would expect that this evidence and the pump-priming of new posts by cancer charity partners will lead to a continued expansion in one to one support both by CNSs as well as opportunities for care co-ordinator roles to be developed. Our ambition is that every cancer patient should have personalised and co-ordinated care.

### National Cancer Survivorship Initiative

- 5.15 The DH is working with Macmillan Cancer Support, NHS Improvement and other partners on the NCSI. The initiative published its vision<sup>25</sup> for improved care and support for people living with and beyond cancer in January 2010.
- 5.16 The vision document summarises a range of evidence that suggests that current follow up arrangements – which usually involve outpatient appointments at cancer centres – are not meeting the medical, psychological, social, spiritual, financial and information needs that people may have following cancer treatment and do not provide value for money

for the NHS. The NCSI has set out five shifts necessary to achieve improved care and support for cancer survivors:

- a cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment;
- a shift towards assessment, information provision and personalised care planning;
- a shift towards support for self-management, based on individual needs and with the appropriate clinical assessment, support and treatment;
- a shift from a single model of clinical follow up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease; and
- a shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures (PROMs) in aftercare services.

5.17 The NCSI has developed a series of principles which should underpin support provided to people living with and beyond cancer. These principles are based on the model of care for people with long term conditions and include that following cancer treatment people should be offered:

- a personalised, risk stratified pathway of care, following assessment and care planning. The assessment will include needs associated with the individual, the disease and the treatment. The pathway will include an end of treatment record summary shared between the cancer centre and primary care team and the care plan will be co-ordinated so that it addresses the full range of needs of those with co-morbidities;
- support to self-manage, where appropriate, after the appropriate assessment, support and treatment. The pathway will include education programmes and information provision to enhance individuals' ability to exercise choice and control and build confidence to self-manage;
- access to appropriate information and support including access to lifestyle advice and interventions, including physical activity programmes and vocational rehabilitation support;
- access to case management and co-ordination support and/or specialist services. Case management support may be appropriate for those with

co-morbidities while some cancer survivors will need the support of specialist services, for example, for those with ongoing chronic disease or for the late effects of cancer treatment;

- planned and informed transition from paediatric to young person to adult services, where appropriate so that there is a seamless transition to adult services and to reduce the number of children and young people who may be “lost to follow up”. Children and young people who have been affected by cancer also need support to minimise disruption to education or entry to first employment; and
- new pathways of care which are underpinned by care co-ordination systems, robust remote surveillance and rapid access to appropriate services if there is suspicion of further disease.

- 5.18 The NCSI has been engaging service users, clinicians and commissioners to develop new models of care and to provide evidence to demonstrate that, through investment in new models of care, there are opportunities to improve quality and efficiency of services. This work in progress includes an economic evaluation of current cancer follow-up arrangements.
- 5.19 In order to support commissioners to commission risk stratified pathways of care for cancer survivors, during 2011 the NCSI will continue to develop the evidence for quality and efficiency benefits of new models of care.
- 5.20 The NCSI is developing and testing new pathways of care which can demonstrate improvements in patient outcomes and experience alongside reductions in unnecessary outpatient appointments and unplanned hospital admissions. Specific work on the pathway for lung cancer will be undertaken in 2011 to evaluate the impact of multi-professional and palliative care input throughout the pathway for those with active and advanced disease.
- 5.21 With more people surviving cancer there is now a greater recognition of the need for rehabilitation to deal with the late effects of treatment or the physical effects of the disease itself. Making better use of social models could improve the experience of survivors and provide better support for carers. Additional funding is available to the NHS for re-ablement, to enable post-discharge support for patients to avoid hospital readmissions.
- 5.22 Many people living with cancer are also living with other long-term conditions. This means that care needs to be personalised and coordinated so that it is tailored to individuals' needs. In many cases models of care and support for cancer survivors are generic with those for people with long-term conditions. In some areas, specialist cancer specific services and support are needed.

5.23 Cancer treatment is often invasive or intensive. This is often necessary to provide the best possible chance of achieving a positive outcome. However, as a result, some patients will be left with ongoing side effects from treatment, which may only become apparent some time after treatment has concluded. We want to see better recording of the late effects of cancer treatment, improved information for patients and access to specialist services for the late effects of cancer treatment. The NCSI will continue to develop evidence and good practice principles to support the development of specialist services for patients with long-term effects of cancer and cancer treatment.

### Patient Reported Outcome Measures (PROMs)

5.24 The outcomes reported by patients are as important as clinical indicators. In order to improve understanding of the quality of life outcomes for cancer survivors, the NCSI is developing a national survey of cancer survivors to be piloted in 2011. The information provided by this survey and the wider routine use of PROMs with cancer survivors will enable commissioners and providers to better understand how services can improve quality of life and outcomes for cancer survivors, and then to take the necessary action to ensure that services meet their needs.

### Carers

5.25 Carers, family and friends play a critical role in supporting many cancer patients. Improving the support for people living with and beyond cancer also requires improved support for carers. The Carers Strategy set out four priority areas for improved support, which apply to people caring for cancer patients as much as for any other condition:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages;
- enabling those with caring responsibilities to fulfil their educational and employment potential;
- personalised support both for carers and those they support, enabling them to have a family and community life; and
- supporting carers to remain mentally and physically well.

5.26 Many of the actions set out in this chapter will improve the quality of support available to carers as well as that for patients.

## End of life care

- 5.27 Since 28% of all deaths are due to cancer it is clear that many patients still require end of life care services and support. DH published its End of Life Care Strategy<sup>26</sup> in 2008 and momentum is building on implementation. The single national measure of progress on place of death is showing signs of improvement, with more people being enabled to die at home.
- 5.28 In order to incentivise investment in appropriate end of life care services, work is underway to develop recommendations for a funding system that will cover dedicated palliative care provided by the NHS, a hospice or any appropriate provider. The review will report back by the summer of 2011.
- 5.29 There is a range of work in hand to improve the planning and coordination of care and to capture patient and carer experience. The national Dying Matters Coalition is also working to break the taboo on discussing death and dying. This currently inhibits both the public and professionals from having the key conversations which would permit proper care planning and understanding of patients' and carers' needs and wishes.

# 6. Improving outcomes for cancer patients: better treatment

## Introduction

6.1 Ensuring that all cancer patients receive the appropriate treatment, delivered to a high standard, is critical to improving cancer outcomes. The right treatment can also be the most cost effective treatment. The quality of treatment has already improved significantly, with more widespread and rapid access to the latest forms of surgery, radiotherapy and drugs as well as the establishment of local and specialist multidisciplinary teams (MDTs) across the country. However, there is more to do. Improving the quality of cancer treatment necessarily requires action from providers but it is for commissioners to ensure that the necessary action is taken so that the patients they serve are receiving a high quality of service and that the steps outlined in this chapter are acted upon.

## Improving access to and the quality of surgery

6.2 Advances in surgical techniques and centralisation of complex surgery mean that the quality of cancer surgery has improved with more operations being carried out by specialist surgeons with expertise in particular procedures, resulting in better outcomes, less invasive procedures and shorter recovery times. The hoped for improvements in early diagnosis, combined with the impact of rising incidence, mean that demands for surgical oncology are likely to increase and this needs to be planned for.

6.3 The benefits of successful surgery are clear: improved survival and reduced costs from the ongoing treatment required to treat cancer which has spread. In order to deliver improved access to high quality surgery, the NHS needs to:

- promote the uptake of the latest surgical techniques, ensuring that the existing surgical workforce receives appropriate training to do this;
- reduce regional variation in access to surgery; and
- improve intervention rates for older people who could benefit, ensuring that age alone is never a barrier to the most appropriate treatment.

### Promoting the uptake of the latest surgical techniques

- 6.4 Historically there has been unacceptable variation in access to high quality surgery and central action has been needed to speed up the uptake of the latest surgical techniques. For example, NICE recommended that laparoscopic colorectal resection should be offered to all suitable patients in 2006. However, because of the shortage of trained surgeons, a DH waiver to the technology appraisal guidance was put in place. In order to address the shortfall in surgeons with suitable skills and experience to perform laparoscopic surgery, a national training programme (LAPCO) was established (through the National Cancer Action Team) to accelerate adoption of this technique. LAPCO continues to have high levels of engagement from consultant colorectal surgeons, with currently over 150 consultants on the programme. As a result we are now in the position to be able to offer choice for all appropriate patients and the waiver has recently been lifted.
- 6.5 As discussed in chapter 8, there need to be the right financial incentives in the system to ensure that providers move rapidly to train their clinicians on any new surgical techniques. While we investigate the best approach to tackling this, there is likely to continue to be a need for central support for such programmes.

### Reducing regional variations

- 6.6 There are considerable geographical variations in access to surgery. For example, while England as a whole lags behind comparable countries in terms of potentially curative surgery for lung cancer, the 2009 National Lung Cancer Audit<sup>27</sup> showed that the resection rate varies from less than 5% in some networks to more than 25% in others. It is not acceptable to have such variations across the country.

### Improving intervention rates for older people

- 6.7 There is evidence that older people are less likely to receive surgery than younger people, irrespective of the existence of co-morbidities. The National Cancer Equality Initiative has identified a range of steps to address this, including piloting patient-level equality audits, testing tools to help clinicians assess patients according to their biological rather than chronological age and offering tailored packages of support to older patients. These actions should help improve active treatment rates for radiotherapy and chemotherapy, as well as surgery.
- 6.8 The focus on improving cancer survival and mortality rates and to improve patient experience should be a sufficient lever to ensure the necessary focus on access to high quality surgery. In order to support these levers:

- it will be necessary to ensure that commissioners and providers, health and well-being boards, the public and patients are provided with data about regional variations in intervention rates for older people;
- DH will investigate incentives to ensure that clinicians are rapidly trained in new surgical techniques;
- in the meantime, we will continue to fund any appropriate national training programmes centrally; and
- DH will ensure that the results from the older people's work will be fully disseminated.

## Radiotherapy

- 6.9 Access to radiotherapy is critical to improving outcomes and, to improve outcomes from radiotherapy, there must be equitable access to high quality, safe, timely, protocol-driven quality-controlled services focused around patients' needs. Detailed modelling<sup>28</sup> suggests that 52% of cancer patients should receive radiotherapy as part of their treatment. In 2007, it was estimated that only 37% of cancer patients accessed this treatment. While radiotherapy capacity has increased, the demand has not increased at the rate previously predicted and there remain variations in activity across the country.
- 6.10 Good information is essential as a way of benchmarking access to radiotherapy services across the country. Now that the Radiotherapy Dataset (RTDS) is fully implemented, we will make sure that the data is routinely published and that commissioners and providers are provided with benchmarked data about their performance. A detailed analysis of the RTDS will be undertaken to ensure that the metrics in the National Radiotherapy Advisory Group (NRAG) report remain meaningful and current.
- 6.11 The Impact Assessment to this Strategy notes that the NAO report *Delivering the Cancer Reform Strategy* (2010) highlighted that there is a wide variation in throughput per radiotherapy machine in England. If an average throughput of 8,700 fractions per machine per year could be achieved across all centres, up to 20% more patients could be treated without the need for significant extra capital investment in radiotherapy capacity. The NAO reported that the average capacity of a RT machine is currently 7,000 fractions per year, and has changed little since the Cancer Reform Strategy (CRS) was published in 2007. This in part is due to trusts not being willing to pay for out-of-hours servicing and upgrades. Any future RT contracts between commissioners and providers will need to reflect this.

However, the overall effect, in line with QIPP, is to reduce the average cost per fraction for machines that do deliver 8,700 fractions per year.

- 6.12 In order to ensure that the NHS has appropriate funding to make full use of existing radiotherapy capacity, and to continue with a modest increase in capacity over the Spending Review (SR) period, the Government will be making available additional investment over the next four years.
- 6.13 Improved outcomes can also be delivered by ensuring that patients have access to high quality modern radiotherapy techniques, comparable to those used in other European countries, to improve cure rates and improve patients' experience by minimising any long-term side effects of treatment.
- 6.14 One example of high quality modern radiotherapy is Proton Beam Therapy (PBT). This is a very precise form of radiotherapy that can be effective in treating a number of cancers and avoiding damage to critical tissues near the tumour. This is particularly important in treating tumours near the central nervous system. We are currently exploring options for developing PBT facilities in England to treat up to 1,700 patients per year. However, these facilities will take time to develop. In order to ensure that all high priority patients with a need for PBT get access to this cutting-edge treatment, additional funding will be provided over the next four years to treat patients (predominantly children) abroad. Based on our assessment of clinical need, this will benefit 400 patients per year by 2014/15.
- 6.15 We say in chapter 8 that we wish to incentivise new techniques, particularly Intensity-Modulated Radiation Treatment (IMRT), through tariffs. At the same time, during 2011, the National Cancer Action Team will support radiotherapy services to introduce these services and we will look at other mechanisms, such as Quality Standards, to promote their introduction.
- 6.16 Outcomes from radiotherapy can also be improved by improving the quality control of radiotherapy provided. During 2011/12, DH will look at what measures would support the delivery of this.

### **Delivering safe, high quality chemotherapy services**

- 6.17 Work is also underway to improve the quality, safety and convenience of chemotherapy services. The National Chemotherapy Advisory Group (NCAG) set out a series of recommendations to address the serious concerns highlighted by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report<sup>29</sup> into chemotherapy, published in 2008. These recommendations remain highly relevant and could be used in developing Quality Standards.

- 6.18 Although further work is required in establishing acute oncology services to ensure that chemotherapy patients receive appropriate care if they are admitted to hospital as an emergency, good progress has been made by some services in implementing NCAG's recommendations. Improving the quality and safety of chemotherapy services can make an important contribution to delivering on the patient safety domain of *Transparency in outcomes: NHS Outcomes Framework 2011/12*. It is also important to delivering improved patient experience.
- 6.19 Moving forward, the priorities will be:
- for NHS commissioners to use financial incentives and contractual arrangements to improve quality and choice, to encourage reductions in emergency admissions and to reward improvements in patient experience. To achieve this NHS commissioners may wish to set requirements about the introduction of e-prescribing, door to needle time for patients with neutropenic sepsis and acute oncology services;
  - to improve the collection and publication of data on chemotherapy activity, outcomes and costs, the chemotherapy dataset will be introduced in April 2012 and this should provide commissioners, providers and others with invaluable information; and
  - to enhance the information available to patients on the benefits and toxicities of treatment.

### Access to cancer drugs

- 6.20 The use of systemic anti-cancer therapy has increased markedly over the past decade, with a number of new effective regimens becoming available. This has led to undoubted benefits for very many patients with improved cure or long-term remission rates for some and prolongation of life and/or improvements in quality of life for others. However, it has also created cost and capacity pressures for the NHS given that new drugs are often used in addition to surgery and radiotherapy, as well as existing forms of cancer drugs.
- 6.21 There is evidence that the UK is a relatively low user of some cancer drugs and that patients may be treated more conservatively than in other countries. It is clear that clinicians have not always had the freedom to prescribe the drugs that they feel could benefit their patients. Clinicians and patients have repeatedly expressed frustration with this.

- 6.22 Over the next three years, the DH will be working towards a new system of pricing for medicines, where the price of the drug will be linked to its assessed value. Value-based pricing will help to ensure licensed and effective drugs are available to NHS clinicians and patients at a price to the NHS that reflects the value they bring. Value-based pricing will be introduced from 2014, when the existing Pharmaceutical Price Regulation Scheme (PPRS) expires. In the interim period, the DH is committed to introducing the Cancer Drugs Fund to enable clinicians to prescribe the treatments which they feel are most appropriate for their patients. Using the Cancer Drugs Fund in the interim and value-based pricing for the longer term, we will move to an NHS where patients will be confident that, where their clinicians believe a particular drug is the most appropriate and effective one for them, then the NHS will be better able to provide it.
- 6.23 The details of how the Cancer Drugs Fund, which will provide £200 million a year in additional funding, will operate are currently subject to consultation. However, it is envisaged that it will cover treatments which are not routinely available on the NHS, which fall into four main categories:
- drugs which have yet to be appraised by NICE;
  - drugs which will not be considered by NICE due to the small patient population for which they are licensed, but which are not covered by specialised commissioning arrangements;
  - drugs which have not been recommended by NICE, mainly on the grounds of cost effectiveness; and
  - drugs which cannot be appraised by NICE, as clinicians wish to use them outside their licensed indication to treat forms of cancer with a similar biology of disease to that for which they are licensed (off-label treatment).
- 6.24 £50 million of additional in-year funding, released from savings in central DH budgets, was allocated to strategic health authorities to support improved access to cancer drugs in 2010/11. The Rarer Cancers Foundation has estimated the interim funding will benefit over 2,000 patients up to 31 March 2011 and that the longer-term Fund could benefit over 10,000 patients each year.<sup>30</sup>
- 6.25 The Cancer Drugs Fund will be important in enabling an accurate estimate to be developed of the extent of demand for drugs which are not routinely funded by the NHS. It will also be important in assessing the benefits that these treatments deliver in routine NHS practice. For these reasons it will

be important that audit data are collected on drugs prescribed through the Fund. At a local level, this information will be valuable in managing allocation and prioritisation of the funding. At a national level, it may be helpful to monitor the arrangements to ensure the Fund is fully and appropriately utilised. And over time it will help to improve the available evidence on how these drugs perform in real-world clinical practice. The National Cancer Action Team is also monitoring demand on the interim funding on a regular basis, which will inform the development of the main fund.

## Targeted medicine

- 6.26 Advances in knowledge of genetics and biochemical pathways are now being translated into new targeted drugs. This means that drugs will be able to be targeted at smaller groups of patients with a particular genetic characteristic, enabling improved efficacy, more accurate dosing and sparing patients who will not benefit from possible side effects. Suitable patients are identified through a variety of tests. Examples include the HER2 test which predicts whether a breast cancer patient will respond to trastuzumab or lapatinib. Similarly the K-RAS test can help predict how well a bowel cancer patient will respond to cetuximab. Many more examples of targeted treatment are expected to become available in the near future.
- 6.27 In October 2010, the Technology Strategy Board, DH and others announced a project bringing together government, researchers and business in a major initiative designed to place the UK at the centre of a revolution in the diagnosis and treatment of disease. The new programme – the Stratified Medicines Innovation Platform – will run funding competitions in early 2011, worth up to £11 million, targeting innovative research and development in areas such as tumour profiling to improve cancer care and developing biomarkers for more effective drugs. In partnership with this initiative, Cancer Research UK will carry out a two-year project to collect genetic data from tumours and information on how gene faults affect patient survival, helping research to develop new cancer drugs targeted at specific genetic mutations.
- 6.28 To capitalise on the possibilities offered by targeted treatments, the NHS needs access to complex molecular diagnostic testing. In response to the House of Lords' report on Genomic Medicine, the Government has established the Human Genomics Strategy Group to consider the implications of such new developments and their impact on future healthcare services. As such tests become increasingly more integrated into

the diagnostic pathway, DH will develop a commissioning and funding structure to enable the efficient delivery of high quality molecular diagnostic testing through centres of excellence.

### Stem cell transplantation

- 6.29 In January 2010, DH asked NHS Blood and Transplant (NHSBT) to lead a review of UK bone marrow and umbilical cord blood programmes, which provide stem cell units for transplant. The report, published in December 2010, has twenty recommendations and DH will follow with interest how service providers and the NHS respond to the challenges set out in the report.
- 6.30 The NHS cord blood bank was set up in 1996 to collect, process, store and supply cord blood, and is currently supported in five hospitals. A key priority is delivering benefits to improve patients' chances of finding a matched sample. NHS cord blood collection is focused at hospitals which have a high number of births from currently under-represented Black and Ethnic Minority populations. About 40% of donations in the NHS cord blood bank are from mothers from these communities. We currently have in place business plans with NHSBT to increase the amount of stored cord blood units to 20,000 by 2013.

### Inpatient stays and emergency admissions

- 6.31 The large majority of cancer patients do not want to be admitted to hospital unless it is absolutely necessary and wish to be in hospital for as short a time as possible when this is necessary. Surveys also show that people would prefer to be cared for and to die at home. This also has the benefit of freeing up NHS resources which can be redeployed to treat more patients and deliver the latest treatments.
- 6.32 As reported by the NAO, good progress has been made in reducing the number of inpatient days per year for cancer patients and the rise in emergency admissions has been slowed down. However, the NAO report also noted that inpatient admissions per new cancer diagnosis varied from 1.7 to 3.2 between PCTs in 2008/09. If every PCT met the inpatient admissions per new cancer diagnosis of the best performing quartile, 532,000 bed days could be saved, equivalent to around £106 million each year. This shows there is scope to go much further. And these further reductions in inpatient days and emergency admissions will represent a very significant contribution to the efficiency savings that the NHS needs to make.

6.33 The NAO reported that the average length of stay for inpatient cancer admissions varied from 5.1 to 10.1 days between PCTs in 2008/09. If every PCT had the same length of stay as the average for PCTs in the best performing quartile, then even with no overall reduction in inpatient admissions, 566,000 bed days could be saved, equivalent to around £113 million each year. NHS Improvement is already leading a Transforming Inpatient Care Programme for Cancer. This is promoting:

- day case/23 hour stays for breast surgery and other procedures;
- Enhanced Recovery Programmes for elective cancer surgery;
- approaches to reduce avoidable emergency admissions; and
- reducing lengths of stay for those who do need to be admitted as emergencies.

6.34 Chapter 8 explains that we plan to develop tariffs to incentivise quality and productivity in terms of inpatient care and avoidance of emergency admissions. In addition, to improve the quality of care and experience for patients and to maximise the scope for savings:

- lessons learned from the Transforming Inpatient Care Programme will be disseminated to providers and commissioners;
- we will collate and publish information on admissions, lengths of stay and bed days by commissioner and by provider Trust; and
- implementation of the end of life care strategy will encourage the development of community-based services for people in the final phase of life.

6.35 Readmission rates will be included in the cross-Government Public Services Transparency Framework. Current formulations of the indicator exclude cancer, because in some situations readmissions are expected. DH will be considering how cancer can be included in this indicator as part of a wider piece of work to understand better how readmission rates should be interpreted.

## Supporting quality services

### Effective multidisciplinary team working

6.36 MDT working has led to improved decision-making, more co-ordinated patient care, and improvement in the overall quality of care. A survey of 2050 MDT members in September 2009 found that there is an

overwhelming consensus that MDTs are beneficial to patient care and should remain the cornerstone of cancer treatment. MDTs bring together staff with the necessary knowledge, skills and experience to ensure high quality diagnosis, treatment and care for patients with cancer. MDT working has been advocated in each of the NICE Improving Outcomes Guidance reports and is strongly supported by clinicians.

### Peer review

6.37 Peer review has provided critical insights into the quality of cancer care across England. Links are now being made between the results from Peer Review and the work of the Care Quality Commission. We recognise, however, that Peer Review is very time consuming for Trusts, and work is underway to consider how the burden of peer review might be reduced by 40%. That work includes consideration of how the process of Peer Review might be streamlined, and how the Care Quality Commission's regulatory activity in this sector might be refined to ensure the burden of regulation is risk based, proportionate and focused where it is most effective, while continuing to provide an overall assurance of essential levels of safety and quality.

### National Clinical Audit

6.38 Another method for measuring the quality of care delivered by MDTs and stimulating improvement is through national clinical audits. There are currently four nationally designated clinical audits relating to different cancers:

- the National Lung Cancer Audit (LUCADA);
- the National Bowel Cancer Audit (NBOCAP);
- the National Head and Neck Cancer Audit (DAHNO); and
- the Oesophagogastric cancer audit.

6.39 National clinical audits for different cancers are helping to drive up service quality. The current audits will be maintained and we would expect new audits to be introduced over time. In the cancer field an audit of prostate cancer is needed to stimulate improvements in quality and outcomes. We will ensure there is no duplication of effort for the service in relation to cancer peer review.

# 7. Improving outcomes for cancer patients: reducing inequalities

## Introduction

- 7.1 Tackling health inequalities in England is essential to improving outcomes and achieving cancer survival rates which match the best performing countries in the world. *Equity and Excellence: Liberating the NHS* makes clear the Government's ambition to reduce health inequalities and improve the health of those with the poorest outcomes.
- 7.2 Incidence and mortality rates from cancer are higher in disadvantaged groups and areas, leading to worse outcomes and lowering our overall performance. Therefore the greatest scope to make rapid improvements is by focussing activity on disadvantaged groups and areas.
- 7.3 As with many health conditions, there is a range of inequalities in the outcomes and experience of cancer patients. These can occur at every stage of the patient pathway, including in awareness, incidence, access to treatment and care, patient experience, survival and mortality. They can also affect a range of groups in society, including socio-economically disadvantaged groups and areas, black and minority ethnic groups, older or younger people, men or women, people with disabilities, people from particular religions or with particular beliefs and the lesbian, gay, bisexual and transgender (LGBT) community.

## National Cancer Equality Initiative (NCEI)

- 7.4 Since its establishment in 2008, the NCEI has undertaken a range of activities, including the publication of the major report *Reducing cancer inequality: evidence, progress and making it happen* in March 2010.<sup>31</sup> This set out a series of recommended national and local actions to reduce inequalities in cancer care around: data collection, analysis and publication; targeted interventions; training, development and research; evaluation and monitoring; and embedding equality. All of these are highly relevant to cancer services in the new environment.
- 7.5 The work of the NCEI was recognised at the 2010 Civil Service Diversity and Equality Awards, where the NCEI won the award for Leading Change in Diversity and Equality.

- 7.6 Advancing equality and reducing inequalities are clearly important to the cancer community. In preparing this strategy, over 35 submissions were received to the mailbox which directly related to equality issues. There was broad support for the work of the NCEI, with comments relating to four themes:
- better data are required to improve the understanding of inequalities and develop key performance indicators to measure improvement;
  - social deprivation requires more use of social marketing techniques and behavioural economics to better target people with prevention and symptom awareness messages;
  - under-treatment of older people is unacceptable. More needs to be done to understand this issue and better equip the professionals on decision making in this area; and
  - accessible information and informed choice requires the roll out of information prescriptions and targeted information for different groups.
- 7.7 In order to support the service in taking forward the recommended actions set out in *Reducing cancer inequality: evidence, progress and making it happen* and to ensure that equality issues are taken into account as we focus on improving outcomes, the NCEI advisory group has been transformed into an implementation advisory group to assess and advise on local and national implementation.
- 7.8 The NCEI will continue to gather evidence on the nature, extent and causes of cancer inequalities; advise other parts of the National Cancer Programme on action; and identify and spread good practice.

### Developing the evidence base on inequalities

- 7.9 The NCEI report set out several equality research priorities which are being discussed with the NCIN and the National Cancer Research Institute (NCRI). In addition, the NIHR National Cancer Research Network is exploring inequalities in access to clinical trials and whether steps are need to improve access in any patient group.
- 7.10 To explore the relationship between schizophrenia and bowel cancer, where research has shown that schizophrenics have a 40% increased chance of developing bowel cancer, NHS Cancer Screening Programmes has commissioned researchers in Oxford and London to undertake a detailed study. The study began in February 2010 and is expected to report in early 2012.

- 7.11 The results of the national cancer patient experience survey also provide invaluable insights into equality issues, as patients were asked to provide details on their age, gender, and ethnicity. Patients were also asked about any disabilities they had: deafness/severe hearing impairment; blindness/partially sighted; long standing physical condition; learning disability; mental health conditions; and long standing illness. For the first time, we also asked patients about their sexual orientation, and 87% of patients were willing to give us this information (5% preferred not to answer and 8% did not answer the question at all). Headline equality results from the survey are in Box 2:

**Box 2 – Equality results of the Cancer Patient Experience Survey 2010**

White cancer patients report a more positive experience than other ethnic groups – particular differences were noted on questions around receiving understandable answers, being given enough care after discharge, and staff working well together

Younger people are the least positive about their experience, particularly around understanding completely what was wrong with them

Older people are less likely to have access to a clinical nurse specialist

Men are generally more positive about their care than women, particularly around staff and staff working together

People with a disability or long term condition reported a less positive experience than other patients across a wide range of issues measured in the survey. This was particularly marked for patients with a mental health condition or a learning disability

Non-heterosexual patients reported less positive experience, especially in relation to communication and (broadly) being treated with respect and dignity

Despite what might be expected, there is no statistically significant link between deprivation and patient experience, taking all quintiles of deprivation together

People with rarer forms of cancer in general reported a poorer experience of their treatment and care than people with more common forms cancer

- 7.12 Commissioners will wish to encourage providers to take note of these differences and to consider positive action to address the distinct needs of people from different groups. In particular, those wishing to drive improvements in patient experience through contracts may wish to identify

particular groups where improvement is required. The survey data will also be made widely available to researchers and policy makers to encourage a wide range of analysis on equality issues.

### Targeted interventions

- 7.13 As a result of the work of the NCEI, a number of targeted interventions are being developed to address equality issues which have been identified.
- 7.14 There is now evidence that older people are not always receiving the same standard of treatment as younger patients. Sometimes healthcare professionals make assumptions about an older person's preferences about treatment and a decision that an older person will not be able to cope with treatment is often made without fully assessing their overall physical health. Work is ongoing to support clinicians by making sure they have accurate information about an older person's ability to benefit from cancer treatment rather than making assumptions on the basis of age, including:
- the DH and Macmillan Cancer Support are jointly funding a two year pilot programme to improve intervention rates for people over 70 who have a cancer diagnosis. The project aims to identify, test and evaluate a simpler way to comprehensively assess an older person for cancer treatment, provide practical support and information to aid patient/practitioner decision-making and train professionals involved in this pathway to promote age equality and address age discrimination. Trail-blazer health and well-being boards may well have a role to play also. Pilot sites have recently been confirmed, with sites going live for a 12 month period; and
  - the Pharmaceutical Oncology Initiative, in partnership with DH, is commissioning research to explore the extent to which age is a factor in treatment decisions for a range of cancers, as well as the extent to which clinical attitudes vary across different cancer types and in different countries. The results will be available in the first half of 2011.
- 7.15 There are links between race and cancer that are complex and which vary between different populations. It also recognised that patient experience surveys have shown that BME groups, in general, report a worse experience of treatment and care. The National Cancer Action Team (NCAT) has been working with BME charities and Cancer Networks to provide a national voice to BME cancer patients and to understand better why they report a poorer experience.

- 7.16 Given that fewer men take up bowel screening than women, DH commissioned the Men's Health Forum to look at why this might be and to recommend actions that will encourage more men to actively consider taking up the offer of screening. A conference will be held in January 2011 to discuss the results and generate advice and ideas for the final report, which will be disseminated via local public health services and screening centres.

### Applying a human rights approach to delivering personalised cancer care

- 7.17 As well as targeting interventions to address specific equality issues, tackling inequalities will require that every patient is offered personalised care, which addresses their particular needs rather than the perceived needs of their demographic group. For example, a patient may be a black older male, who comes from a disadvantaged community. Ensuring he receives appropriate care and that his needs are met in the way that he wishes them to be met will require a personalised approach.
- 7.18 Applying a human rights-based approach lends itself well to supporting cancer services in commissioning and delivering personalised care. DH is therefore supporting Macmillan Cancer Support in undertaking a project to apply a human rights approach to the delivery of cancer treatment and care. The purpose of the project is to assist services in moving away from using process measures to assess progress on equality issues, towards measuring the outcomes that really matter to patients. The outputs from this project will be available in 2011 and we will work with Macmillan Cancer Support to ensure that they are applied to promoting equality in cancer services.

### Embedding equality

- 7.19 Equality issues should not be an add-on, but rather should be embedded by all aspects of cancer services in implementing this Strategy. At a national level, the NCEI is working closely with other national initiatives such as the National Awareness and Early Diagnosis Initiative (NAEDI) and the National Cancer Survivorship Initiative (NCSI) to ensure that equality issues are addressed at each stage of the patient pathway.
- 7.20 At a commissioner level, information will be provided to consortia on the equality and inequality characteristics of their cancer populations, as well as how their performance compares with other areas. The equality metrics, available through the Equality Portal, will provide commissioners,

stakeholders and the public with readily accessible and comparable information on equality issues. Commissioners will wish to use this information to work with providers to tackle embedded inequalities in cancer care at every stage of the pathway.

- 7.21 At a provider level, Multi-Disciplinary Teams (MDTs) are being encouraged to embed equalities into clinical practice. We will develop and distribute patient characteristics profiles to MDTs. In future, MDT Health Equity Audits will form part of National Cancer Peer Review Programme.

## 8. Autonomy, accountability and democratic legitimacy: commissioning and levers

### Introduction

- 8.1 Commissioning is key to delivering improvements in outcomes and this chapter sets out how we will improve the quality of the commissioning of cancer services, ensuring that decisions are focused on the needs of patients.
- 8.2 The quality of commissioning of cancer services has historically been variable. The recent National Audit Office (NAO) report commented on the often inadequate commissioning around cancer services. The new commissioning arrangements give us the opportunity to get this right.

### Commissioning of cancer services

- 8.3 Commissioning for cancer is particularly complex. There are many different types of cancer, each requiring different interventions, with a different care pathway. The other important element of complexity is the co-ordination of services across the treatment and care pathway for the patient. For each cancer this involves health and social care teams in general practice, in the community, in acute general hospitals and in specialist centres.
- 8.4 Where the diagnosis and treatment of cancer are rare, they require specialised commissioning, which are not appropriate for GP consortia. The areas of cancer commissioning which are currently covered by national or regional specialised commissioning will continue to be subject to similar arrangements, through the NHS Commissioning Board.
- 8.5 A significant amount of cancer care is best commissioned for populations covering 1½ – 2 million. This includes specialist surgical services for upper gastrointestinal, urological, gynaecological, head and neck cancers and chemotherapy and radiotherapy. Where population size requirements mean that a single GP consortium is too small to commission a particular service, then GP consortia will wish to work collaboratively. GP consortia will be able to decide whether they wish to identify a lead consortium for commissioning more specialised cancer services (outside of NHS Commissioning Board commissioning) or to do so through commissioning support organisations. GP consortia will need support for commissioning,

including for cancer services. Much is already available, but more will need to be provided and it will be for GP consortia to source the support they deem is appropriate.

- 8.6 The Government's response to the NHS White Paper consultations, *Liberating the NHS: legislative framework and next steps*, set out detail about the proposed health and wellbeing boards in every upper-tier local authority, which will provide a mechanism for bringing together local NHS, public health and social care commissioners. This could provide a forum for the development of cross-cutting commissioning approaches to improve cancer services. Health and wellbeing boards will include elected representatives, local HealthWatch and key local commissioners for health and social care, including GP consortia and Directors of Public Health, adult social care and children's services.
- 8.7 The health and wellbeing boards will provide more effective engagement between local government and NHS commissioners. There will be a statutory obligation for the local authority and NHS commissioners to participate as members of the board and act in partnership. This will ensure that the services commissioned can better reflect local need and priorities.
- 8.8 To ensure joined-up commissioning at a local level, local authorities and GP consortia will each have an equal and explicit obligation to prepare the joint strategic needs assessment (JSNA), and to do so through the health and wellbeing board. To build on the JSNA, and to ensure that collaboration is the norm, all health and wellbeing boards should have to develop a high-level "joint health and wellbeing strategy" that spans the NHS, social care, public health and could potentially consider wider health determinants such as housing, or education.
- 8.9 The joint health and wellbeing strategy should provide the overarching framework within which commissioning plans for the NHS, social care, public health and other services the health and wellbeing board agrees are relevant are developed. At present JSNA obligations extend only to its production, not its application. To address this, the forthcoming Health and Social Care Bill will place a duty on commissioners to have regard to the JSNA and the joint health and wellbeing strategy when exercising their functions.
- 8.10 As some cancers are more common than others, NICE has defined appropriate population and activity thresholds for different cancer services in a series of evidence-based cancer Improving Outcomes Guidance documents (IOGs).<sup>32</sup> In order to ensure quality care for patients, these IOGs will continue to be a feature of all commissioned services.

- 8.11 The library of Quality Standards being developed by NICE will be an important resource for commissioners in identifying issues to prioritise and will enable scrutiny of the extent to which they are commissioning high quality care. It is envisaged that the Commissioning Outcomes Framework, which will be used to incentivise high quality commissioning, will be closely aligned with the NICE Quality Standards. And for commissioners, the Commissioning for Quality and Innovation (CQUIN) payment framework will be important for ensuring the implementation of NICE Quality Standards by providers.
- 8.12 In developing a comprehensive suite of Quality Standards, NICE has made good early progress on key topics such as patient experience, end of life care and breast cancer. Further Quality Standards for colorectal, lung, ovarian and prostate cancer have been prioritised as part of the next tranche of the programme. These will be developed in 2011, and NICE will use them to support the production of more detailed commissioning guidance, to which GP consortia must have regard when contracting for services. NICE have also been asked to assess the suitability of developing a Quality Standard on chemotherapy. The need for further Quality Standards to support the development of cancer services is also being considered as part of arrangements for defining the full suite of future standards. In the meantime, commissioners and providers can continue to draw on the clinical guidelines and Improving Outcomes Guidance that NICE has already developed for cancer services.
- 8.13 It is important that patients get access to new and emerging treatments and techniques as soon as possible during the transition. We will therefore publish advice to commissioners and providers on photodynamic therapy, stereotactic body radiotherapy and robotic surgery for prostate cancer in 2011.
- 8.14 The consultation for *Transparency in outcomes: a framework for adult social care*<sup>33</sup> sets out plans to expand NICE's remit to cover social care, which will allow for whole pathway Quality Standards which capture social care interventions to be developed from 2012.
- 8.15 The DH and the National Cancer Action Team have previously provided commissioners with a range of guidance and support, such as the Cancer Commissioning Toolkit and the Cancer Commissioning Guidance. For the future, these will be further developed and focused on what works best in supporting pathfinder GP consortia. We will also develop, in 2011, a cancer commissioning support pack to enable commissioners to access in one place the key information they will need to discharge their functions effectively.

This will include possible CQUIN goals, such as for improving patient experience.

- 8.16 As GP consortia develop, it will be important that the DH and then the NHS Commissioning Board is able to respond to the developing needs of commissioners in relation to cancer. During transition cancer networks will support pathfinder GP consortia in improving the commissioning of cancer services. Once the new commissioning arrangements are fully established it will be for consortia to determine whether to continue getting advice and support from networks or to seek such support elsewhere.

### Rewarding high quality care

- 8.17 In line with the comments in the recent NAO report, we need to ensure that we have better activity information and full clarity about costs for different services, and the right incentives to reward quality and efficiency. We are currently assessing what needs to be done in terms of responding effectively to the NAO recommendations.
- 8.18 In terms of having the right incentives to reward quality and efficiency, the DH has been working for some years to develop tariffs for chemotherapy and radiotherapy, and this work will be accelerated. In addition to taking forward the tariffs for chemotherapy and radiotherapy, during 2011/12 the DH will investigate the potential development of a range of tariffs to incentivise high quality, cost-effective services, including:
- breast cancer screening;
  - bowel cancer screening (FOBT, flexible sigmoidoscopy and colonoscopy elements);
  - day case and 23 hour breast surgery, including one-stop axillary surgery;
  - new surgical techniques as they arise (so that there are incentives to develop appropriate training programmes quickly);
  - avoidance of emergency admissions and readmissions;
  - the newest radiotherapy techniques, in particular Intensity Modulated Radiation Therapy (IMRT) (once the radiotherapy tariff has been introduced);
  - good quality, personalised care pathways for cancer survivors – so that patients do not have to attend appointments unnecessarily, but all get the support and help they need to maximise the quality of life; and
  - services for patients experiencing the late effects of cancer.

## Supporting regulation

8.19 *Equity and excellence: Liberating the NHS* made clear that the regulatory regime for providers of NHS services will be strengthened. From a cancer perspective, this will mean that the Care Quality Commission (CQC) will receive the following information feeds:

- screening quality assurance findings;
- peer review findings (compliance scores and immediate risks);
- national cancer patient experience survey results; and
- case-mix adjusted clinical outcome data, as these become available.

8.20 CQC will take a proportionate risk-based approach to regulation and inspection. Where CQC has concerns about a provider or if, for example, peer review indicates there may be cause for concern, it will take a more pro-active approach. Failure to comply with the registration requirements is an offence and CQC has a wide range of independent enforcement powers, ranging from the issue of a warning notice that requires improvement within a specified time, to prosecution, and the power to cancel a provider's registration, removing its ability to provide regulated activities.

8.21 Through HealthWatch England, a part of the CQC, there should be scope to tackle cancer inequality issues. In 2011 we will develop links between the National Cancer Equalities Initiative (NCEI) and HealthWatch.

# Annex A

## Details of stakeholder engagement

1. Large numbers of organisations and individuals have been involved in the development of this Strategy. Engagement meetings have been held with:
  - expert advisory groups on cancer, including the Bowel Cancer Advisory Group, the CRS Breast Cancer Advisory Group, the Lung Cancer and Mesothelioma Advisory Group, the Prostate Cancer Advisory Group, the Children and Young People's IOG Advisory Group, the National Chemotherapy Implementation Advisory Group, National Radiotherapy Implementation Group, the Bowel Screening Advisory Committee, the Advisory Committee on Breast Cancer Screening, the Advisory Committee on Cervical Screening, National Cancer Equality Initiative Implementation Advisory Group, and the CRS Patient Experience Advisory Group
  - GPs including GP commissioners;
  - clinicians and managers working throughout the NHS;
  - Royal Colleges;
  - patients, including through workshops specifically for service users;
  - cancer charities;
  - the Cancer Reform Strategy Advisory Board;
  - the steering groups for the National Awareness and Early Diagnosis Initiative, the National Cancer Equality Initiative and the National Cancer Survivorship Initiative, and the CRS Patient Experience Working Group;
  - groups of experts who updated their CRS visions of how services for cancer type groupings would look in 2015; and
  - the healthcare industry, through the Pharmaceutical Oncology Initiative.

2. In addition, over 200 submissions were received to a mailbox which was established to ensure that stakeholders could contribute their views to the development process. A summary of the responses received is included in Box 3.

### **Box 3 – summary of submissions to the mailbox**

In total 202 submissions were received to the mailbox, broken down as follows:

- 15 from NHS organisations
- 13 from other professional organisations, such as Royal Colleges
- 106 from Individual Healthcare Professionals
- 33 from charities or coalitions of charities
- 13 from commercial suppliers to the NHS, such as pharmaceutical companies
- 12 from users or patient groups
- 10 from individuals

3. Many organisations have devoted a great deal of constructive thought to how cancer policy should develop in the context of the NHS reforms, including:

Action on Bladder Cancer, Afiya Trust, Beating Bowel Cancer, Brain Tumour Research Campaign, Breakthrough Breast Cancer, Breast Cancer Campaign, Breast Cancer Care, Bowel Cancer UK, Cancer 52, Cancer Campaigning Group, Cancer Research UK, Clic Sargent, GistSupport UK, Independent Cancer Patients, International Brain Tumour Alliance, Leukaemia Care, Leukaemia & Lymphoma Research, Lymphoma Association, Macmillan Cancer Support, Melanoma Taskforce, Myeloma UK, Oesophagael Patients Association, Ovarian Cancer Action, Pancreatic Cancer UK, Rarer Cancers Foundation, Roy Castle Foundation, Samantha Dickson Brain Tumour Trust, Target Ovarian Cancer, Teenage Cancer Trust, The British Lung Foundation, The Prostate Cancer Charity, United Kingdom Lung Cancer Coalition, World Cancer Research Fund

# Annex B

## New evidence supporting the development of this Strategy

### International Cancer Benchmarking Partnership

1. To provide more up to date and detailed estimates of differences in outcome between countries, an international cancer benchmarking partnership has been established between countries known to have high cancer survival (Australia, Canada and Sweden), intermediate survival (Norway) and low survival (Denmark, England, Northern Ireland, and Wales). Initiated by England, this partnership aims to compare survival rates across countries, establish why some nations have better survival than others and share good practice from high performing countries. The partnership is examining survival rates across countries for breast, colorectal, lung and ovarian cancer, for patients who were diagnosed between 1995 and 2007.
2. Findings from the project (see Box 4) suggest that English survival rates continue to lag behind the best performing countries in the partnership and that, with the exception of breast cancer survival, we are not narrowing the “survival gap” to move closer to the best performing countries.

#### **Box 4 – International Cancer Benchmarking Partnership**

Analysis of 2.4 million cancer patients diagnosed in 12 jurisdictions within six countries between 1995 and 2007

Four cancer types studied: Breast, colorectal, lung and ovary

All countries showed improved survival on all four cancers between 1995/99 and 2005/07

UK (only England, Wales and Northern Ireland participated) had the poorest survival at each time period for each cancer

Australia, Canada and Sweden had the best survival

The gap in survival between England and the best countries from 1995/09 and 2005/07 remained unchanged for colorectal cancer (11.0% and 10.7%) with small changes in lung cancer (from 8.1% to 9.2%) and ovarian cancer (from 5.1% to 4.2%)

For breast cancer the gap in five year survival between England and the best countries narrowed from 10.6% to 5.5%

Much of the difference in five year survival for each cancer can be attributed to poor one year survival in England, and poor survival in the elderly

3. We now have internationally comparable data which is more robust and up-to-date than has been possible before. Future modules of the project will be able to drill down into the root causes for these differences between survival rates in England and other countries by studying:
  - population awareness and beliefs (Module 2);
  - GP beliefs and behaviours (Module 3);
  - the causes of diagnosis delays (Module 4); and
  - the extent to which evidence based treatments are applied (Module 5).

### International comparisons of drug usage

4. More information than ever is now available on both the extent and the causes of international variations in drugs usage as a result of a study<sup>34</sup> led by Professor Sir Mike Richards, National Cancer Director, involving DH, clinicians, the pharmaceutical industry, patient representatives, NICE and health informatics specialists. The study looked at use of drugs in 12 disease areas across 14 countries, including the UK, between April 2008 and March 2009. Hormonal cancer drugs, drugs licensed before 1999, between 1999 and 2003 and between 2004 and 2008 were included in the study.
5. The study revealed that the UK:
  - has a low rank for cancer drugs licensed between 2004 and 2008 and that overall usage of drugs in this category is less than a half of the all-country average;
  - has an intermediate rank for cancer drugs licensed between 1999 and 2003 and usage levels are close to the all-country average, although this may overstate the UK's position as lower than average usage was observed for a number of drugs in this category that are used in relatively large patient populations. The absence of a method for standardising usage of cancer products means there is no weighting for differences in the volume usage of individual drugs;
  - has a low rank for cancer drugs launched more than 10 years ago, but usage levels are close to the all-country average; and
  - has an intermediate rank for hormonal cancer drugs and usage levels are close to the all-country average.
6. Explanations for the UK's relative position include:
  - the impact of NICE technology appraisals – for cancer, this has contributed to limited use of some newer drugs, though patterns of use are likely to change with the establishment of the Cancer Drugs Fund;

- the impact of service capacity and planning – for cancer, it will be important to plan for sufficient capacity to be available to meet the increased demands caused by rising incidence and developments in treatment; and
- the impact of clinical culture and perceptions – for cancer, there is growing evidence that UK clinicians may treat some patients, such as older people, less intensively than some of their international counterparts, and this may help to explain why UK uptake of some drugs can be lower than the international average even where they have a positive NICE appraisal. Practice will have to be looked at to ensure it is consistent with the requirements of the Equality Act 2010 and the proposed public sector equality duty, particularly around removing unjustified age discrimination in healthcare.

### Routes to diagnosis

7. Research into the way in which patients are first diagnosed reinforces the link between emergency presentation and poor outcomes. The study,<sup>35</sup> undertaken by the National Cancer Intelligence Network and the South West Public Health Observatory using linked hospital and cancer registry data for over 225,000 patients diagnosed with cancer in 2007, reveals that:
  - approximately 23% of cancer patients were first diagnosed via emergency presentations;
  - there were major variations between tumour types in the prominence of emergency presentations – for example, for melanoma this route represented 3% of cases, for breast 4%, for colorectal 25%, for lung 38% and for brain 58%;
  - emergency presentations were most prominent in the youngest patients (0-24) and older (75 plus) age groups;
  - significant variations in emergency presentation rates occur by commissioner; and
  - emergency presentation is strongly associated with poorer survival.
8. These findings are reinforced by the national cancer patient experience survey, which found that approximately 20% of patients did not visit their GP prior to being diagnosed with cancer. Although some of these patients will have been diagnosed as a result of screening, many will have been diagnosed following an emergency presentation. Box 5 shows the disparity in one-year survival rates associated with emergency presentation, when compared with other routes for a range of cancers.

**Box 5 – one-year survival rates for patients first presenting as an emergency, compared to other routes to diagnosis**

Tumour type	One-year relative survival	
	All routes to diagnosis	Emergency presentation
Acute leukaemia	40%	38% *
Bladder	72%	35%
Brain & CNS	44%	32%
Breast (f)	97%	53%
Cervix	86%	49%
Chronic leukaemia	78%	54%
Colorectal	73%	48%
Kidney	66%	33%
Larynx	83%	43%
Lung	26%	9%
Melanoma	97%	61%
Multiple myeloma	66%	46%
Non-Hodgkin lymphoma	74%	46%
Oesophagus	39%	21%
Oral	82%	56%
Other	45%	15%
Ovary	69%	42%
Pancreas	14%	8%
Prostate	95%	54%
Stomach	38%	22%
Testis	98%	89%
Uterus	90%	57%

\*The difference in relative survival rates between all routes and only those presenting as an emergency was statistically significant for all tumour types except for acute leukaemia

### Review of quality of cancer registration

9. In relation to the quality of outcomes achieved in England, a good deal of work has been undertaken to investigate the nature, extent and causes of variation in outcomes when compared to other countries. In August 2010, an editorial in the *British Medical Journal*<sup>36</sup> argued that cancer registration is incomplete and questioned the validity of UK cancer survival statistics, asserting that survival relative to other countries was understated and that survival is a misleading measure of the quality of country's outcomes.
10. In order to investigate this claim, a rapid review of the completeness and quality of cancer registration was undertaken. A rapid review panel was established including a number of leading epidemiologists to evaluate data coming from the registries. All UK cancer registries provided additional analyses to assess the robustness of data collected to ascertain whether patients with a good prognosis had been missed and whether the survival duration of those who died had been underestimated. Phase one of the review concluded that deficiencies in cancer registration do not explain the differences in survival rates that have been observed. A plan to deliver improvements in the accuracy of registry of survival rate data is being developed.

### Clinical trials of screening

11. There have also been extremely encouraging developments in the evidence base for how cancers can be diagnosed at an earlier stage. For example, a randomised control trial published in April 2010 found that flexible sigmoidoscopy, a one off procedure, both significantly reduces the incidence of, and mortality from, bowel cancer, potentially saving 3,000 lives every year. This is a very promising development, as bowel cancer is England's second biggest cancer killer. Flexible sigmoidoscopy has the potential to save even more lives in future, and we will better understand its life-saving potential as we monitor the trial results for longer.

### Measurement of service quality through peer review

12. In relation to improving the quality of cancer care, the latest findings from the National Cancer Peer Review Programme for breast, lung, upper GI, urology and gynaecological cancers show that there has been an improvement in the quality of multidisciplinary teams (MDTs), with greater compliance with peer review measures. However, there is a small number of teams (around 5% of the approximately 900 MDTs reviewed in the last round) where performance is unacceptably poor, with scores below 50%. The poor quality of a small minority of MDTs will need to be tackled if improvements in the quality of cancer care are to be sustained and built upon.

## Cancer Peer Review Programme

### Comparison of Median Values 2004 – 2008 and 2009 – 2010

MDTs	2004/8 – Median Values	2009/10 – Median Values	Change
Breast	77%	86%	+9%
Lung	74%	87%	+13%
Gynae (L)	72%	85%	+13%
Gynae (S)	83%	85%	+2%
Upper GI (L)	67%	83%	+15%
Upper GI (OG)	78%	81%	+3%
Upper GI (Panc)			
Urology (L)	70%	82%	+12%
Urology (S)	77%	78%	+1%
Testicular	74%	85%	+11%
Penile	89%	67%	-22%

### Patient experience survey

13. In relation to improving patients' experience of treatment and care, the results of the 2010 National Cancer Patient Experience Survey are now available. All cancer types were included in the survey for the first time, and patients from all 158 eligible Trusts participated in the survey. Over 100,000 adult patients who had received cancer treatment as either an inpatient or a day case between January and March 2010 were invited to participate and nearly 70,000 people did so. Over 60% of respondents had been diagnosed within the past year. Key findings include:

- the experience of patients with forms of cancer where comparable data are available (lung, breast, bowel and prostate cancer) have largely improved since 2000;
- the experience of men with prostate cancer, which was notably inferior to that of patients with other cancers, has significantly improved and prostate cancer is no longer an outlier;
- patients with rarer forms of cancer generally report a significantly worse experience of their treatment and care than patients with the four most common forms of cancer (breast, bowel, lung and prostate); and
- the care provided by clinical nurse specialists (CNSs) is valued highly by patients, with those who had access to a CNS (84%) reporting a significantly more positive experience than those who did not.

14. A number of the key findings are summarised in Box 6.

**Box 6 – key findings on the experience of cancer patients**

81% thought first hospital appointment was as soon as necessary

83% of patients said their cancer diagnosis was given sensitively

66% of patients were given easy-to-understand written information at the time of diagnosis

72% of patients were definitely involved in choosing their cancer treatment

84% of patients said they had confidence and trust in all of the doctors treating them

84% of patients were given the name of a clinical nurse specialist (CNS)

91% of patients said their CNS listened carefully to them

67% of patients had confidence and trust in the ward nurses treating them

50% of patients said hospital staff gave information about how to get financial help

88% of patients were given the right amount of information

82% of patients said they were always treated with dignity and respect

15. A national report has been produced, along with bespoke Trust level reports, broken down by cancer type where numbers allow and benchmarked against other Trusts. The data has been analysed by age, gender, ethnicity, disability, sexual orientation and socio-economic group. The survey data has also been made freely available to allow a series of analyses to be undertaken on such a rich data source and to enable commissioners and providers to focus on the areas for quality improvement locally.

**National Audit Office study of cancer services**

16. The National Audit Office (NAO) published on 18 November 2010 a value for money study examining progress in three key areas of action announced in the Cancer Reform Strategy:
- improving the quality of information on cancer services so as to provide a basis for better decision-making and more effective assessment of performance;

- strengthening cancer commissioning so as to ensure that services meet the health needs of their local population, performance is monitored and outcomes achieved are evaluated against the resources used; and
  - making better use of resources so as to deliver high quality outcomes and free up expenditure to meet the increasing demand for services.
17. Overall, the NAO identified that progress has been made but that there is still much more to do. On improving the quality of information on cancer, the National Cancer Intelligence Network (NCIN) has succeeded in improving the collection and coordination of information by bringing together data specialists, organisations and datasets and linking clinical, demographic and performance data from a range of sources. This has resulted in the generation of new analyses and insights, as well as the provision of clearer and more accessible information for cancer commissioners. However, further work is required to fill gaps on the stage of patients' cancer at diagnosis, as well as to improve data on chemotherapy activity and outcomes. In addition, more can be done to reduce duplication in the publication of cancer data, saving resources and improving the timeliness of the availability of key information on cancer services.
18. On strengthening the commissioning of cancer services, progress has been made in improving the information available to commissioners and in ensuring local delivery against key Cancer Reform Strategy commitments on issues such as waiting times and screening coverage. However, the NAO found that too many commissioners have failed to focus on improving value for money in cancer services and that they lack an understanding of what drives costs in cancer care, particularly in radiotherapy, chemotherapy and the location of care.
19. On better use of resources, the NAO found that the actual cost of cancer services is understated by programme budget data as these do not take into account costs associated with the pre-diagnosis phase. Overall, the cost of cancer care in 2008/09 was estimated to be £6.3 billion, including £1.2 billion of activity before cancer treatment (including screening and diagnostic investigations which may or may not lead to a cancer diagnosis) and in primary care which was not previously classified as relating to cancer. The NAO also commented on the variation in spend on cancer between PCTs and between years. Progress has been made in reducing inpatient hospital bed days caused by cancer, with a reduction of 281,000 inpatient bed days between 2006/07 and 2008/09, despite rising incidence. This is the result of a combination of shorter lengths of stay and increasing the number of patients

treated as day cases. However, the NAO believes that there is significant scope for further savings in cancer services, particularly through reducing the variations in the productivity of radiotherapy departments, inpatient admissions and average length of stay. There is also a pressing need to improve the way in which cancer activity is coded and costed, particularly for outpatient care.

20. While not pre-empting the outcome of the Public Accounts Committee consideration of issues raised in the NAO report (hearing was on 7 December 2010), this Strategy seeks to respond to the NAO's criticisms.

# Annex C

## Executive summary of waiting times report

### Background

1. In July 2010 Ministers asked the National Cancer Director, Professor Sir Mike Richards to lead a review of the Cancer Reform Strategy (CRS, 2007) to be completed by Winter 2010. As part of this review, the current set of waiting time standards have been revisited to ensure they retain clinical justification and remain appropriate. This was in line with the Coalition Government's commitment to focus on outcomes rather than process targets, except where the latter are clinically justified.
2. The review has been overseen by the Going Further on Cancer Waits (GFOCW) Advisory Group, chaired by the National Cancer Director. To support the review, the DH Cancer Policy Team has undertaken a range of activities including a literature review and drawing on comparative policy information across the four devolved administrations.
3. The views of a wide range of health professionals, patient groups, charities and NHS managers have been sought through meetings of existing cancer advisory groups, written communication and a dedicated engagement event.
4. Four key questions have been considered:
  - Should cancer waiting time standards be retained i.e. do they remain clinically justified?
  - Should any specific cancer waiting time standards be changed?
  - Should specific cancer types be excluded from the standards?
  - How can the system be improved?

### Findings from the review

5. It was noted that all the current cancer waiting time standards (e.g. two week wait; one month (31-day) standard; two month (62-day) standard) are being consistently achieved at a national level. However, some Trusts and local health economies are struggling to achieve the standards.

6. Large scale cancer patient experience surveys involving all acute and specialist NHS Trusts in England were conducted in 2000 and 2010. In the 2010 survey, 68% of cancer patients reported that they had been seen by a hospital doctor within 2 weeks of referral and 91% had been seen within 4 weeks, irrespective of whether they were referred urgently or non urgently. For all tumour groups at least 80% of patients reported being seen within 4 weeks. This represents a considerable improvement over 2000. In 2000, only 66% of all patients surveyed waited less than a month for an appointment with a hospital doctor. For the five tumour groups surveyed other than breast cancer the figure was 57%.
7. The unanimous view of patient groups and cancer charities and the almost unanimous views of clinicians and NHS managers is that the cancer waiting time standards have helped to drive service improvement and have been beneficial for patients. Although it is impossible to quantify whether the targets have led to improvements in cancer survival, almost everyone we consulted felt that the targets had reduced patient anxiety related to delays in being assessed, diagnosed with and treated for cancer. There was overwhelming support from stakeholders for the retention of cancer waiting time standards.
8. Each of the cancer waiting time standards was carefully considered within the review process to assess whether it was still justified or whether it could now be removed in order to reduce the burden of monitoring and management. The unanimous view of the Advisory Group is that all the targets continue to be justified and should be retained.
9. In general, stakeholders felt that the waiting time standards should apply to all types of cancer. Special consideration was given to the issue of waiting times for patients with prostate cancer, as there are clinical indications for waiting for 4-6 weeks between a prostate biopsy and a subsequent MRI scan. It is also recognised that men with prostate cancer may need time to consider treatment options with very different implications. Options were considered that involved excluding prostate cancer from the two month standard and lengthening the standard to 93 days (i.e. 3 months) for this group of patients. On balance, it was agreed that the two month standard should be retained. However, it was also felt that DH should re-emphasise to NHS Trusts that the operational standard of 85% of patients being treated within two months (62 days) of an urgent referral for suspected cancer does not mean that this standard has to be achieved for every cancer type.

10. The diagnostic care pathway for some cancers (e.g. breast and skin cancers) is relatively simple and quicker than for others (e.g. colorectal cancer or head and neck cancers). To achieve an overall standard of 85%, it is reasonable to expect that around 95% of breast cancer and skin cancer patients will be treated within two months, whilst only about 80% of those with more complex pathways will be treated in the same timeframe.
11. Several different options for improving the processes surrounding cancer waiting times were considered. These included: reintroducing suspensions ("stopping the clock"), particularly in relation to patients who want time to think about treatment, and the adoption of different processes for allocating responsibility for patients who breach the standard for those cases who are initially referred to one NHS Trust, but then require onward referral to another Trust for treatment (so called Inter Provider Transfers or IPTs).
12. The Advisory Group noted that suspensions (periods where the waiting time clock is stopped) had been used when the cancer waiting time standards were first introduced. The system was changed when the Referral To Treatment (18 week or RTT) target was introduced, as it was felt to be too burdensome on the NHS to run two processes (Cancer and RTT) in parallel locally. As data relating to time from referral to treatment is still a mandatory data collection, the concerns about the potential burden on the NHS of running two systems would remain. It was further noted that the work done to remove the option to "suspend" a patient had reduced the operational standard for the two month standard from 95% to 85%. The Advisory Group unanimously recommended that the current process should continue.
13. It is recognised that the proportion of breaches (patients waiting longer than the specified time) of the 62 day standard is higher for patients who follow a pathway of care including a referral between providers, an IPT, than for those who are treated at the Trust to which they are initially referred. Mainly this is a reflection on the degree of coordination of care across a cancer network. At present when an IPT patient breaches the two month standard responsibility is shared equally between the referring and the receiving Trust. This may act to the disadvantage of large providers of tertiary services.
14. In considering this issue, the Advisory Group were keen to ensure that patients who are required to transfer between NHS Trusts should not be disadvantaged in terms of timeliness of treatment. Members of the group were also keen to take account of the need for equity in the application of performance assessment between Trusts and of the need for processes to be simple to operate within the NHS.

15. One of the methods considered as an appropriate method of ensuring equity is “breach reallocation”, where responsibility for any service failure is identified in an adjustment to the statistics to ensure the responsible provider on a multi-provider pathway of care is the only trust impacted in any statistical assessment of performance. In practice, the issue of breach reallocation is only an issue for a small number of Trusts with very high IPT numbers. Therefore, on balance, it was not considered necessary or appropriate to change the system as a whole to accommodate these local problems. Instead the Advisory Group recommended that local processes should be developed and piloted where necessary. These might well involve collecting data on day of referral from one Trust to another (e.g. from secondary to tertiary care). Local arrangements for breach allocation could then be negotiated.
16. Usability and ease of access to cancer waiting times information is important for both NHS and non-NHS users. The Advisory Group noted the steps undertaken by DH to ensure the National Statistics on waiting times for suspected and diagnosed cancer patients meet the UK Statistics Authority’s “Code of Practice for Official Statistics” (the subject of a parallel review). The Advisory Group also felt that ongoing lay input into the quality and dissemination of cancer waiting times information would also fulfil the Government’s aims of better information to support choice, commissioning and service quality improvement.

## Conclusions

17. After careful consideration of a wide range of issues related to the current waiting time standards, the Advisory Group were unanimous in their view that these standards have been beneficial for patients and that they should be retained without any changes at a national level.

# Annex D

## Glossary and Abbreviations

**Acute Care** For a disease or illness with rapid onset, severe symptoms and brief duration.

**Adjuvant therapy** A term used to describe additional treatments, such as chemotherapy or radiotherapy, given after cancer surgery.

**Age standardised mortality** Age-standardised rates cover all ages and are standardised to the European Standard Population, expressed per million population. This allows comparisons between populations with different age structures, including between males and females and over time.

**Biomarkers** A cellular or molecular indicator of exposure, disease, or susceptibility to disease.

**Care Quality Commission (CQC)** The Care Quality Commission is the independent regulator of health and social care in England. They regulate care provided by the NHS, local authorities, private companies and voluntary organisations.

**Cancer Network** Organisational model drawing together multiple institutions and agencies to collaboratively deliver cancer care.

**Cancer Registry** A register designed to collect information about the occurrence (incidence) of cancer, the types of cancers that occur and their locations within the body, the extent of cancer at the time of diagnosis (disease stage), and the kinds of treatment that patients receive.

**Chemotherapy** The use of drugs, singly or more usually in multiple combinations, to treat or cure cancer.

**Commissioning** The process of assessing the needs of a local population and putting in place services to meet those needs.

**CQUIN** Commissioning for Quality and Innovation (CQUIN) framework – the CQUIN framework enables those commissioning care to pay for better quality care, helping promote a culture of continuous improvement.

**GP consortia** GPs working in groups to be known as consortia will lead the commissioning of most healthcare services across England. GP consortia are to be statutory bodies accountable for commissioning. Those consortia who will be testing out how this will work in transition are known as “pathfinder consortia”.

**Improving Outcomes Guidance (IOG)** Site specific cancer guidance on the organisation and delivery of cancer services by tumour group, published by the National Institute for Health and Clinical Excellence (NICE)

**Mortality rate** Mortality statistics mean the number of people per population who have died from a particular type of cancer in a year. These figures should be looked at alongside incidence figures and other statistics.

**NHS Commissioning Board** NHS Commissioning Board will have powers devolved to it directly from the Secretary of State. The entity that will have the responsibility for holding consortia to account and for allocating and accounting for NHS resources. The NHS Board will control and support the GP consortia and GP consortia will be held to account in terms of outcomes, financial performance and operating in a fair and transparent manner when commissioning.

**Operating framework** The Operating Framework sets out the priorities for the NHS for each financial year.

**Peer review** National Cancer Peer Review (NCPR) is a national quality assurance programme for NHS cancer services. The programme involves both self-assessment by cancer service teams and external reviews of teams conducted by professional peers, against nationally agreed “quality measures”.

**Public Health England (PHE)** Subject to passage of the Health and Social Care Bill, PHE will be established within DH in 2012 and will set the overall outcomes framework for public health, accountable to the Secretary of State for Health.

**Quality Accounts** A report on the quality of services published annually by providers of NHS care. Quality accounts are intended to enhance accountability to the public.

**Quality Standards** Set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions, published by the National Institute for Health and Clinical Excellence (NICE).

**Screening** Conducting examinations or tests to detect diseases before symptoms are present. Screening allows for detection of diseases in their early, most treatable stages.

**Survival rate** What survival means is that x% of patients were alive x% years after they were diagnosed.

**Tariff** The tariff is the calculated price for a unit of healthcare activity paid to providers by commissioners.

### Abbreviations used:

**ACBCS:** Advisory Committee on Breast Cancer Screening

**ACCS:** Advisory Committee on Cervical Screening

**CNS:** clinical nurse specialist

**CQC:** Care Quality Commission

**CQUIN:** Commissioning for Quality and Innovation

**CT:** Computed Tomography

**CRS:** Cancer Reform Strategy

**FOBT:** Faecal Occult Blood testing

**FS:** flexible sigmoidoscopy

**HPV:** Human papilloma virus

**HSE:** Health and Safety Executive

**HTA:** Health technology assessment

**IAG:** Implementation Advisory Group

**IOG:** Improving Outcomes Guidance

**ICBP:** International Cancer Benchmarking Partnership

**IMRT:** Intensity Modulated Radiation Therapy

**ISB:** Information Standards Board

**LGBT:** lesbian, gay, bisexual and transgender

**MDT:** multidisciplinary team

**NAEDI:** National Awareness and Early Diagnosis Initiative

**NAO:** National Audit Office

**NCAG:** National Chemotherapy Advisory Group

**NCAT:** National Cancer Action Team

**NCEI:** National Cancer Equality Initiative

**NCEPOD:** National Confidential Enquiry into Patient Outcomes and Death

**NCIN:** National Cancer Intelligence Network

**NCRI:** National Cancer Research Institute

**NCRN:** National Cancer Research Network

**NCSI:** National Cancer Survivorship Initiative

**NHSBT:** NHS Blood and Transplant

**NICE:** National Institute for Health and Clinical Excellence

**NIGB:** National Information Governance Board

**NIHR:** National Institute for Health Research

**NRAG:** National Radiotherapy Advisory Group

**OECD:** Organisation for Economic Co-operation and Development

**PBT:** proton beam therapy

**PHE:** Public Health England

**PPRS:** Pharmaceutical Price Regulation Scheme

**PCRMP:** Prostate Cancer Risk Management Programme

**PSA:** Prostate Specific Antigen

**ROCR:** Review of Central Returns

**RTDS:** Radiotherapy dataset

**QA:** quality assurance

**QIPP:** Quality, Innovation, Productivity and Prevention

**SR:** Spending Review

**UK NSC:** UK National Screening Committee

# Annex E

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