

# Cancer Reform Strategy



# Cancer Reform Strategy

## DH INFORMATION READER BOX

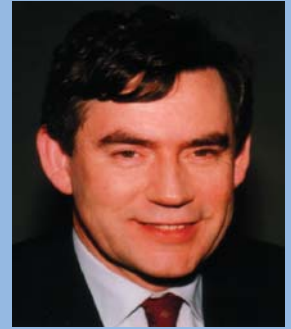
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## Foreword by the Prime Minister



At one time or another every family in Britain will have been touched by the shadow of cancer. Almost one in four people die from the disease and many more are still living with the after effects of cancer today.

Groundbreaking advances in our understanding of cancer and its treatment are leading to significant advances in the quality of care and treatment which cancer patients receive. Over the last ten years falls in mortality rates have saved 60,000 lives and survival rates continue to improve year on year for bowel and breast cancers. And we are investing more than ever before - £15 billion over the next ten years – in researching the cures and treatments of the future, many of which will impact on the lives of cancer patients.

But at the same time there are new challenges. The number of people contracting cancer continues to increase as our population ages and the consequence of successful treatment is that more people are living after cancer than ever before. And because cancer is no longer the death sentence it was, that serves to increase the importance of care for cancer survivors.

Our next steps must reflect the very highest priority that we as a country attach to combating this disease.

Our action on cancer must focus more than ever on prevention and reducing the risk of people developing the disease. Our commitment to rolling out a cervical cancer vaccine to all girls must act as a signal that our understanding of cancers is allowing us to do more than ever before to help all of us stay cancer free. But this must be combined with greater responsibility from individuals to change aspects of their behaviour, such as smoking, to reduce their own risk.

Early diagnosis is vital if we are to achieve a genuinely world-class cancer service. The extensions to screening and early diagnosis which we are setting out in this plan will allow all of us faster and easier access to screening than ever before. Our investment in digital mammography will further improve the already successful breast screening service.

We must do more to ensure treatment is of the highest quality and I believe this plan can act as a road map to a higher standard of care, available to all. Our investment in world-class radiotherapy will ensure all of us have access to the best care when we are most in need.

I welcome the opportunity this strategy has provided for working in partnership with charities such as Cancer Research UK and Macmillan Cancer Support and I look forward to this partnership helping to deliver the improvements we all want to see. We will work closely with Macmillan Cancer Support in developing a survivorship initiative that I believe will make a difference to the lives of all those living with the aftermath of cancer and their carers.

I would like to thank everyone who has contributed to the improvements to cancer services that we have seen in recent years, and I look forward to the truly world class cancer service which I believe this strategy will deliver.

**Gordon Brown**

**The Prime Minister  
Gordon Brown**





## Foreword by the Secretary of State



Each year around 230,000 people in England will be diagnosed with cancer and around 125,000 will die from it. In some way, cancer will touch the lives of every person. Since becoming Secretary of State, the public, NHS professionals and of course patients have repeatedly told me that tackling cancer should continue to be a high priority. I agree.

In 2000 we published the NHS Cancer Plan. At that time too many of our cancer services were failing to meet the expectations of people affected by the disease, or to do justice to the dedication and commitment of the people involved in caring for patients.

Since then, progress has been impressive. Cancer mortality is falling, more patients are surviving and people's experience of cancer services is improving. Of course, the NHS Cancer Plan was a ten year plan and it is important that we finish the job. However there is also much more that we can and must do.

There are significant challenges facing cancer services. Incidence is increasing as our population ages, the inequalities gap for cancer remains too large and although advances in the way we treat cancer are offering new opportunities to cure more patients, they also come at a high cost.

However there are also great opportunities to deliver further improvements and I am optimistic that we can build world class cancer services for everyone, free at the point of need and true to the enduring values of the NHS.

Thanks to the progress made since the publication of the NHS Cancer Plan and the actions we are taking in this strategy, we are now in a position to make ten pledges to patients:

1. More will be done to help you to reduce your risk of developing cancer;
2. An increased likelihood of your cancer being detected earlier;
3. You will have access to high quality treatment at every stage of your cancer journey;
4. Whether you are living with or beyond your cancer, high quality information and support, tailored to your personal needs will be available;
5. Irrespective of who you are or what your background is, the NHS will work to give you access to the best possible cancer experience and outcomes;
6. Your care will be delivered in the most clinically appropriate and convenient setting for you;
7. You will be able to access information about the performance of your cancer services, enabling you to make informed choices which reflect your priorities;
8. Your PCT will be supported in ensuring that the best possible cancer services are available for you;

9. Your NHS cancer services will continue to be properly funded; and
10. We will keep striving to improve the quality of cancer services available.

These pledges are at the heart of the Cancer Reform Strategy. You can read more about the actions that will enable us to keep them on page 13.

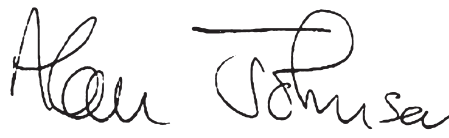
We have set out our commitment to devolve power and authority to local NHS bodies and therefore the way in which we continue to make progress on diseases such as cancer must change. The Cancer Reform Strategy provides a strong foundation for how we will move forward.

During the transition from central direction to more locally driven improvement we are broadening the scope of some existing national requirements for cancer services. For example, we will be offering routine breast screening to older and younger women and we are including second and subsequent cancer treatments in the 31 day maximum waiting time standard rather than restricting it to just the first treatment.

I want to take this opportunity to thank the thousands of healthcare professionals and managers involved in cancer. Their hard work and commitment has made possible the significant progress on cancer already achieved and will be vital as we now start to deliver the actions in this strategy.

I would like to thank everyone who has contributed to the development of this strategy, particularly members of the Advisory Board and working groups who devoted so much time, enthusiasm and creativity to developing the proposals which are central to the actions we are announcing today.

This strategy represents an ambitious programme for cancer services over the next five years and I look forward to working with all the stakeholders involved in cancer as we implement the actions set out today, making real our vision of building a world class cancer service.



**The Rt. Hon. Alan Johnson MP**  
**Secretary of State for Health**

## Executive Summary

1. The Cancer Reform Strategy builds on the progress made since the publication of the NHS Cancer Plan in 2000 and sets a clear direction for cancer services for the next five years. It shows how by 2012 our cancer services can and should become among the best in the world.

2. There has been considerable progress made on cancer over the past decade. Cancer mortality has fallen, survival rates are improving for many cancers and patients' experience of their care has improved. We have also made progress against smoking, detected more cancers early through screening and delivered faster diagnosis and treatment. Multidisciplinary teams now provide more coordinated and higher quality care for patients and there has been considerable financial investment in cancer which has helped to deliver an expanded cancer workforce and more equipment.

3. Significant challenges and opportunities remain which this strategy seeks to address. The incidence of cancer is increasing as people live longer and more people are alive having survived cancer. Our scientific understanding of cancer is improving greatly, providing new opportunities for prevention, early diagnosis and better treatment. There is considerable potential to introduce new service models for cancer which will improve both convenience and outcomes for patients. We also know that we can do more to improve the experience of care for patients, both during and after treatment.

4. The NHS has undergone significant reform since the NHS Cancer Plan was published. New systems for commissioning and financial management have been introduced and we have new ways to provide patients with choice

and incentivise local improvement. This strategy is written in this new context and provides advice and support to local commissioners and providers on how to deliver high quality, cost-effective cancer services.

5. The Cancer Reform Strategy sets out a programme of action across ten areas: six areas of action to improve cancer outcomes and four areas of action to ensure delivery.

### Actions to improve cancer outcomes

#### Preventing cancer

6. Over half of all cancers could be prevented by changes to lifestyle. Taking cross-government action to tackle the major risk factors for cancer, improving awareness and encouraging people to adopt healthy lifestyles is therefore crucial to improving cancer outcomes.

7. Smoking is the single largest preventable risk factor for cancer. As well as maintaining the high price of tobacco and taking action to reduce the availability of illicit tobacco, the government will consult during Spring 2008 on proposals for the next steps in tobacco control and the further regulation of tobacco products, including the display of tobacco at the point of sale, access to tobacco from vending machines and packaging.

8. The evidence linking obesity to cancer has become much stronger since the publication of the NHS Cancer Plan in 2000. The government has committed to developing a cross-government strategy to tackle obesity and this will be published shortly.

9. Excessive alcohol consumption is strongly linked to an increased risk of several cancers. To tackle this, a programme of activity is planned for next year and beyond, including a sustained national communications campaign to improve the public's knowledge of units of alcohol and ensure everyone has the information they need to estimate how much they drink, targeted information and advice for people who drink at harmful levels and consultation on the need for legislation regarding alcohol labelling.

10. Skin cancer incidence is rising rapidly, almost certainly reflecting patterns of behaviour over recent decades. The government will expand the Sunsmart campaign, which is aimed at promoting behaviour change to prevent skin cancer and raising awareness of the early signs of the disease. The Department of Health is reviewing options for regulation of the industry and as a first step will gather more information about the number and distribution of sunbeds and the scale of sunbed use by minors.

11. Vaccination now presents a further opportunity in cancer prevention, specifically for cervical cancer. As announced in October, the government is introducing a national vaccination programme for young girls against the human papillomavirus. This will protect against the strains of the virus which cause around seven out of ten cases of cervical cancer.

12. Given the importance of cancer prevention, PCTs and cancer networks should give high priority to raising public awareness of cancer risk factors.

### **Diagnosing cancer earlier**

13. In general, the earlier a cancer can be diagnosed the greater the chance of a cure. Late diagnosis is the major factor contributing to poor cancer survival rates in this country.

14. Screening is vital to diagnosing some cancers early. To improve and expand cancer screening, the government will:

- Build on progress on cervical cancer screening, by reducing the variation of coverage between PCTs, informing women of the result of their cervical screening test within two weeks of it being taken, using new technologies as and when the research evidence supports this and tackling the falling participation of women aged 25 to 35;
- Extend breast screening to nine screening rounds between 47 and 73 years, with a guarantee that women will have their first screening before the age of 50, facilitated by the roll out of digital mammography;
- Expand the NHS Bowel Cancer Screening Programme from 2010 to invite men and women aged 70 to 75 to take part. By the end of 2010, decisions will be taken about possible roll out to people in their 50s; and
- Commission research on the feasibility of a UK trial of CT screening for lung cancer, working with the National Cancer Research Institute.

15. A new National Awareness and Early Diagnosis Initiative will coordinate a programme of activity to support local interventions to raise public awareness of the signs and symptoms of early cancer and encourage people to seek help sooner. This will include developing a tool for measuring awareness levels and supporting high quality evaluations of pilot projects.

16. We also want to understand more about the nature and extent of delays in cancer diagnosis. A national audit in primary care of newly-diagnosed cancers will be used to make decisions about how best to provide more support to primary care professionals to ensure the early diagnosis of cancer.

### **Ensuring better treatment**

17. We need to build on the successes we have already achieved in cancer treatment to ensure that patients have fast access to high quality treatment for cancer, including surgery, radiotherapy and drug treatment.

18. Excellent progress has been made on reducing waiting times. We will now extend the range of patients who benefit from the current standards:

- The 31 day standard will be extended to cover all cancer treatments;
- In addition to patients referred urgently by their GP, all patients with suspected cancer detected through national screening programmes will in future enter the 62 day pathway;
- Hospital specialists will have the right to ensure that patients who were not referred urgently by their GP, but who have symptoms or signs indicating a high suspicion of cancer, are managed on the 62 day pathway; and
- All patients referred to a specialist with breast symptoms, even if cancer is not suspected, should be seen within two weeks of referral.

19. Surgery cures more patients of cancer than any other intervention and cancer surgery will continue to improve. A pilot training programme for laparoscopic bowel surgery will be established which will be fully evaluated for potential national rollout.

20. To achieve a world class radiotherapy service local investment will be needed both in equipment and workforce. We want to ensure that the recommendations for improving capacity in radiotherapy services that were set out in the National Radiotherapy Advisory Group's report are achieved and that providers have sufficient capacity to meet the 31 day waiting time standard for all radiotherapy, not just first treatment.

21. Drug treatments for cancer have developed substantially over the past 20 years and are set to develop further. It is important that NICE guidance on new technologies is available as soon as possible. In future the default position for all new cancer drugs and significant new licensed indications will be that they will be

referred to NICE, providing that NICE agrees that there is a sufficient patient population and evidence base on which to carry out an appraisal and that there is not a more appropriate alternative mechanism for appraisal. Where possible, appraisal will be carried out in parallel with licensing. The National Cancer Director will repeat his evaluation of NICE-approved cancer drug usage during 2008 to ensure that patients across the country continue to have access to cancer drugs positively appraised by NICE.

22. Current clinical audits do not collect sufficient information to understand why variations in the usage of drugs occur. We will therefore ask all chemotherapy service providers to collect and return an agreed dataset on all patients receiving chemotherapy. Better data collection on chemotherapy activity will also aid PCTs in their planning.

23. PCTs, working with each other in their cancer networks, will want to undertake a review of cancer chemotherapy and develop a strategic framework for chemotherapy services, setting out clear service specifications, taking account of forthcoming advice from the National Chemotherapy Advisory Group's report which is expected in Spring 2008.

### **Living with and beyond cancer**

24. Although patients' experience of their care has improved in recent years, we can do more to support and empower patients throughout their cancer journey.

25. We will improve information for patients through a range product and pathway initiatives. Tumour specific national information pathways will be launched in 2008, making nationally agreed information available to frontline cancer health professionals to offer to patients at key points in their cancer journey. A three-way partnership between Cancerbackup, Cancer Research UK and Macmillan Cancer Support is developing a system to provide sections of content to support the implementation of information prescriptions which will provide patients with high quality information, tailored to their individual needs.

We will also expand the provision of communications skills training for healthcare professionals.

26. Commissioners will want to work with providers to ensure they have robust systems in place to ensure that patients experience good continuity of care. They should give particular consideration to the role of Clinical Nurse Specialists, who play a critical role in cancer care.

27. Cancer patients and their families and carers may need psychological support. Commissioners should work collaboratively to ensure that good psychological support services are available throughout the cancer journey.

28. We also want to improve the access patients have to information on the financial support that may be available to them. Information on financial benefits will be made available on the forthcoming national information pathways from January 2008.

29. As early diagnosis and treatment improves, more people are surviving cancer. A new National Cancer Survivorship Initiative, in partnership with cancer charities, clinicians and patients, will consider a range of approaches to improving the services and support available for cancer survivors.

### **Reducing cancer inequalities**

30. There are major inequalities in cancer incidence, access to services and outcomes, according to deprivation, race, age, gender, disability, religion and sexual orientation. This strategy therefore places a high priority on ensuring that action is taken to reduce these inequalities.

31. The government will begin a National Cancer Equality Initiative, bringing together key stakeholders from the professions, voluntary sector, academia and equality groups to develop research proposals on cancer inequalities, test interventions and advise on the development of wider policy. The National Cancer Equality Initiative will focus initially on optimising data collection to enhance our understanding of the inequalities that exist, promoting research to fill

gaps in the evidence and spreading good practice.

### **Delivering care in the appropriate setting**

32. New models of care can bring considerable advantages to patients. This strategy sets out a range of ways in which service models for cancer could be improved, based on two key principles: first that care should be delivered locally wherever possible to maximise patient convenience; and second that services should be centralised where necessary to improve outcomes.

33. In all cases, care must be delivered by providers which conform to national standards such as the Improving Outcomes Guidance and which are fully integrated with other services within the cancer network.

34. GPs and primary care professionals must have quick and easy access to relevant diagnostic tests, both to exclude cancer in patients with a low chance of having cancer and to diagnose cancer quickly in patients with a high chance of having cancer.

35. Regarding inpatient care for cancer, there are significant opportunities to shift some services from inpatient to ambulatory care. Evidence from successful pilots and international experience confirms that this shift improves patient experience and outcomes and increases the efficiency of services. The Cancer Services Collaborative Improvement Partnership and the Cancer Action Team are developing a programme of work on inpatient management to support local implementation of these new service models.

## **Drivers for delivery**

### **Using information to improve quality and choice**

36. Collecting and using improved information on different aspects of cancer services and outcomes is central to delivering this strategy. Better information will enhance quality, inform commissioning and promote choice.

37. National surveys will be developed to collect information on awareness of and attitudes to

cancer risk factors and symptoms among different groups within society and on patients' experience of treatment and care.

38. We will also collect defined datasets of clinical outcomes information as part of the national model contract. To co-ordinate this work, a National Cancer Intelligence Network (NCIN) will be established, building, maintaining and quality assuring a new national repository of cancer data. The partner organisations within the National Cancer Research Institute (NCRI) will help fund research on the data collated by the NCIN, facilitating a more informed analysis of cancer services than has ever been possible before. The NCIN will publish an annual report detailing the changes to clinical outcomes and patient experience across the country.

### **Stronger commissioning**

39. Everyone with a commitment to delivering world class cancer services should have a role to play in helping deliver this strategy. However, strong commissioning will be particularly important in driving service quality and ensuring value for money.

40. Cancer networks will support PCTs in their commissioning role. They will provide the mechanism through which PCTs can carry out their partnership responsibilities effectively and they will act as agents for commissioners, maintaining the dialogue with clinical teams and users, agreeing clinical guidelines and pathways and driving forward innovative, high quality care.

41. A guide for cancer commissioners is currently in development, which will set out the appropriate level for the commissioning of different cancer services. Also, we are developing an electronic commissioning toolkit to provide commissioners with comparative data on incidence, survival and mortality from cancer and on information available from national sources such as hospital episode statistics.

42. Changes to Payment by Results will be made taking account of findings from a review of PbR and cancer.

### **Funding world class cancer care**

43. The government is committed to funding world class cancer services but also expects the NHS to deliver value for money.

44. New investment is being made to fund necessary increases in activity relating to the increased incidence and longer survival of cancer and also to fund innovations deemed cost-effective by NICE and the new vaccination programme for HPV.

45. PCTs will have the funds to cover the commitments made in the Cancer Reform Strategy but will have to ensure that expenditure which does not benefit patients is eliminated.

### **Building for the future**

46. New opportunities and challenges will continue to arise so we will need to continue to reassess the progress made in tackling cancer and refine our approach to reflect new developments.

47. In order to ensure that we build for the future of cancer services, we will:

- Support workforce development and training;
- Conduct good quality horizon-scanning to plan for new developments and innovations;
- Increase support for research;
- Continue working in partnership with stakeholders;
- Provide national leadership and support; and
- Publish annual reports on progress.

# What the Cancer Reform Strategy means for patients

The actions we are taking are intended to ensure that every person has access to world class NHS services at every point of the cancer pathway. Our pledge to patients is that:

## **1. More will be done to help you to reduce your risk of developing cancer:**

- Young girls will be offered vaccination to significantly reduce their risk of developing cervical cancer;
- Awareness of risk factors will be tracked and action taken to improve public awareness; and
- We will go further on tackling risk factors for cancer such as smoking, obesity and excessive exposure to ultraviolet light.

## **2. There will be an increased likelihood of your cancer being detected earlier:**

- Screening programmes for cervical, bowel and breast cancer will be improved and expanded;
- A new National Awareness and Early Diagnosis Initiative will be launched to measure symptom awareness, develop key messages and test, evaluate and roll out interventions to improve it; and
- A national audit of primary care will be developed, examining the extent of any delays in diagnosis and identifying the support which will help GPs identify potential cancers earlier.

## **3. You will have access to high quality treatment at every stage of your cancer journey:**

- More patients will be covered by existing waiting time standards;
- Further action will be taken to reduce cancer waiting times for all forms of treatment, including surgery, radiotherapy and chemotherapy;
- Expanding the capacity and effectiveness of radiotherapy services will be a priority;
- Action will be taken to ensure faster access to clinically and cost effective treatments; and
- Variations in treatment usage, both internationally and within England, will be monitored.

## **4. Whether you are living with or beyond your cancer, high quality information and support, tailored to your personal needs will be available:**

- Action will be taken to inform and empower patients so that they can play as active a role in decisions about their care and treatment as they wish;
- Priority will be given to ensuring there is adequate provision of Clinical Nurse Specialists;
- Support will be available to help patients cope with the cost of cancer, including advice on benefits and returning to work; and



- A new National Cancer Survivorship Initiative will be established to improve the ongoing support available to people who have been treated for cancer.

**5. Irrespective of who you are or what your background is, the NHS will work to give you access to the best possible cancer experience and outcomes:**

- A National Cancer Equality Initiative will be launched to optimise data collection to enhance our understanding of the inequalities that exist, promoting research to fill gaps in the evidence and spread good practice; and
- Challenging goals will be set to reduce mortality in every cancer network area by 2012, with particular attention being paid to reducing inequalities.

**6. Your care will be delivered in the most clinically appropriate and convenient setting for you:**

- Irrespective of where treatment is delivered, it will be fully integrated;
- The Improving Outcomes Guidance will be fully implemented and services will only be delivered by providers which conform to these important national standards; and
- Opportunities to reduce the length of hospital stay and minimise emergency admissions will be taken, benefiting patients and saving resources.

**7. You will be able to access information about the performance of your cancer services, enabling you to make informed choices which reflect your priorities:**

- Information on levels of public awareness about cancer, the experience reported by patients and the clinical outcomes of different hospitals will be collected, analysed and published by the new National Cancer Intelligence Network; and

- This information will be used to enable patients to make choices, hospital teams to identify areas of weakness and commissioners to incentivise improvements in quality.

**8. Your PCT will be supported in ensuring that the best possible cancer services are available for you:**

- Cancer networks will support PCTs in commissioning high quality, safe and effective cancer services;
- Tools will be made available to PCTs to enable them to commission effectively and benchmark their performance, including national guidance, peer review data and a commissioning guide and toolkit; and
- Patients will play a central role in helping commission cancer services.

**9. Your NHS cancer services will continue to be properly funded:**

- Following record increases in spending, we will continue to make money available to the NHS to meet the challenge of rising cancer incidence and new treatments;
- By reducing spending on services which do not make a difference to patients, we will be able to invest more in services which do;
- Variations in spending on cancer by PCTs will be closely monitored, as will differences in international spending; and
- Cancer spending will continue to be focused on cost effective interventions which make a difference to patients.

**10. We will keep striving to improve the quality of cancer services available:**

- Training programmes will be organised to ensure a skilled and flexible cancer workforce;
- Funding will be made available to the NHS to invest in the latest cancer equipment and progress on this will be monitored;

- Regular expert horizon scanning will be undertaken to ensure that we identify and prepare for new developments which can help patients;
- The government will work closely with the voluntary sector and others to ensure that research into all aspects of cancer remains a priority; and
- The National Cancer Director will continue to provide leadership and annual reports on the progress made on delivering this Strategy will be published.

# Part 1: Introduction



# Chapter 1:

## The challenge of cancer

### Chapter summary

- Substantial progress has been made in cancer in the last decade, particularly since the publication of the NHS Cancer Plan in 2000. However, major challenges remain;
- This Cancer Reform Strategy aims to: save more lives; improve patients' quality of life; reduce inequalities; build for the future; enable cancer care to be delivered in the best place at the right time and achieve maximum value for money;
- The strategy has been developed in consultation and partnership with a broad spectrum of groups and individuals involved in cancer; and
- While national oversight of cancer services will remain, implementation of this strategy at a local level will depend on strong commissioning and continued partnership working.

### Introduction

1.1 Every year around 230,000 people in England will be diagnosed with cancer and around 125,000 will die from the disease, making it the leading cause of mortality in people under the age of 75.

1.2 Cancer is also a major cause of concern to the public. In a Cancer Research UK survey over a quarter of people said that cancer was the thing they most feared, topping the list over Alzheimer's, a heart attack and terrorism.<sup>1</sup> A Cancerbackup poll found over three quarters

of adults think cancer should be a national health priority.<sup>2</sup>

### Progress on cancer

1.3 During the 1980s and 1990s the UK was in the unacceptable position of having survival rates that were amongst the poorest in Western Europe. Patients often waited long periods for diagnosis and treatment. Coordination of care between all the healthcare professionals involved in cancer was often lacking and standards of care varied widely across the country. That is why the government set out

**Figure 1: Biggest causes of premature death for people aged under 75 in England in 2005**

Disease	Percentage
Cancer	38%
Circulatory	28%
Respiratory	9%
External (Accidents, Suicides, Homicides)	7%
Digestive	6%

ambitious plans to improve cancer services in the NHS Cancer Plan, published in 2000.

1.4 Since then outcomes have improved:

- Cancer mortality in people under 75 fell by over 17% between 1996 and 2005. This equates to approximately 60,000 lives saved over this period;
- In 1996, 71,000 people under 75 died from cancer in England. Ten years later in 2006 this figure had dropped to 62,000;
- As shown by Figure 2 below, this means we expect to exceed our target of a minimum 20% reduction in cancer mortality by 2010 from the 1995/97 rate;
- Survival rates for some cancers (such as colorectal (bowel) and breast cancer) are improving year on year, in line with other European countries (see Figure 3 below); and

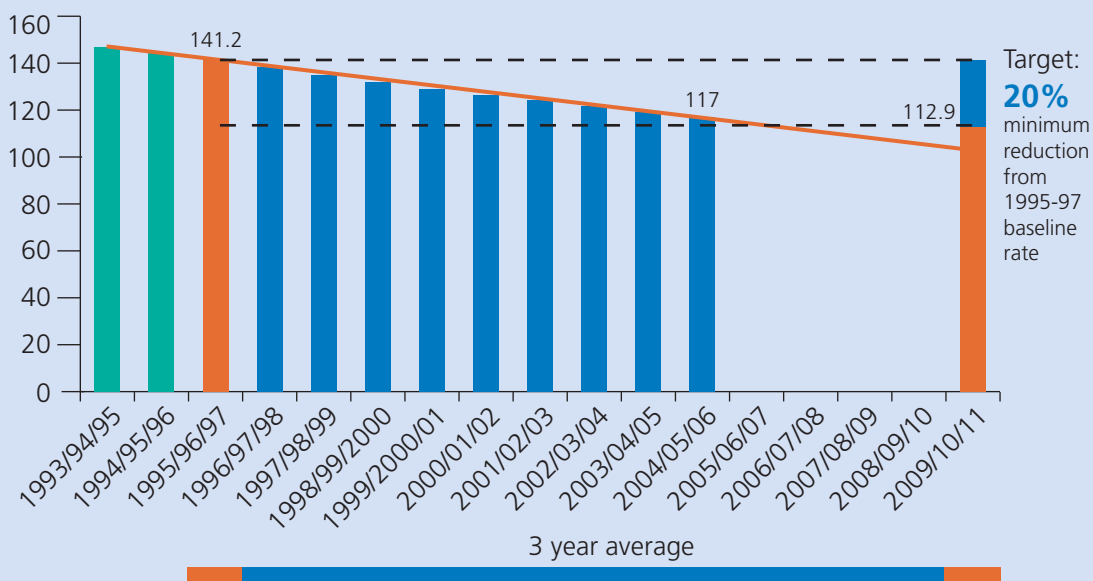
- Patients are reporting an improved experience of their own treatment and care (see Figure 9 in chapter 5).

1.5 As Figure 4 below shows, in 2006, the UK ranked ninth out of 28 European countries for male cancer mortality (where the first has the lowest mortality) and 22nd out of 28 for female mortality. The high mortality in females reflects higher smoking prevalence rates in the 1980s and 1990s in comparison to other European countries.

1.6 Since the implementation of the NHS Cancer Plan we now have:

- **Better prevention** – action on tobacco has led to a fall in smoking rates (from 28% of the population in 1998 to 24% in 2005), amounting to 1.6 million fewer smokers;

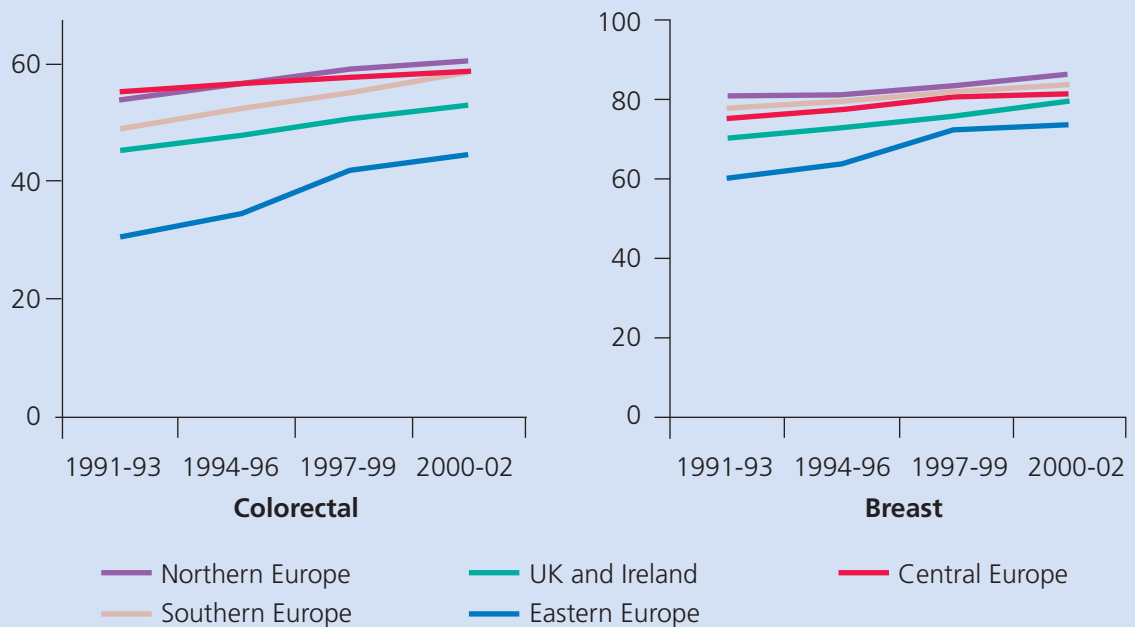
Figure 2: Cancer mortality (persons under age 75) from all cancers in England, 1993 to 2006



Rates are calculated using the European Standard Population to take account of differences in age structure. ICD9 data for 1993 to 1998 and 2000 have been adjusted to be comparable with ICD10 data for 1999 and 2001 onwards. \*Exponential projection based on data for the 10 years 1997-2006.

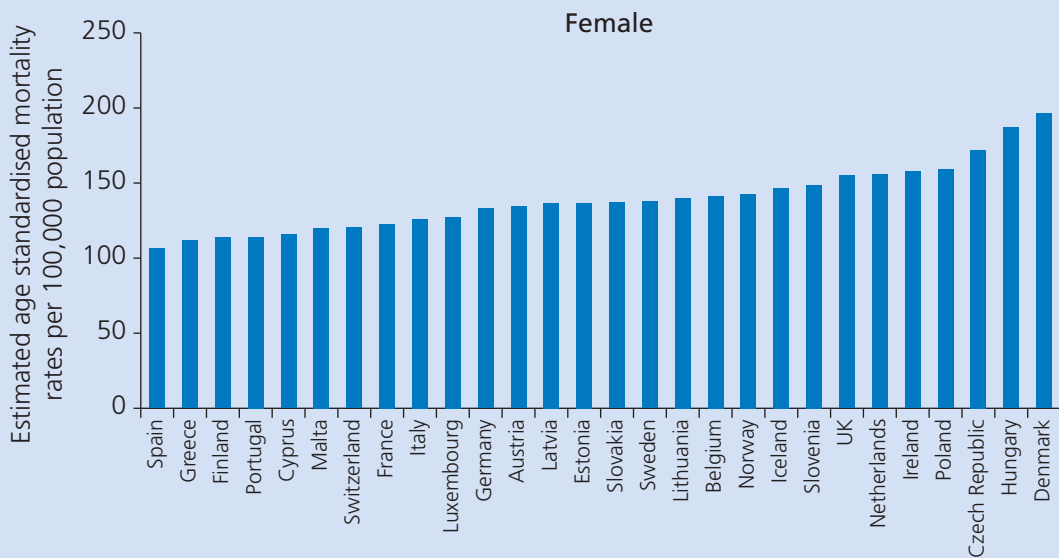
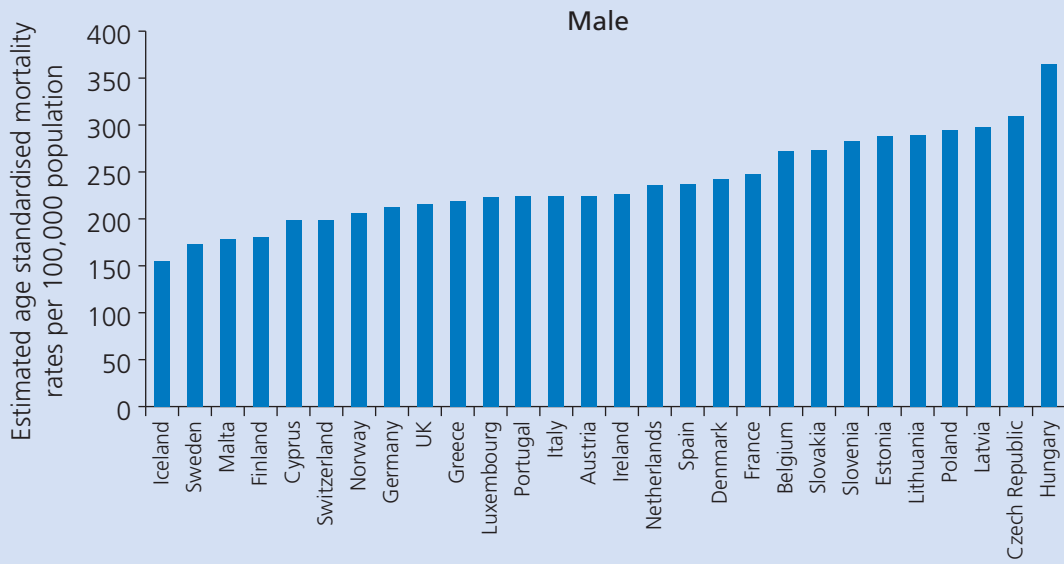
Source: ONS (ICD9 140-209; ICD10 C00-C97)

**Figure 3: Five year period survival profiles (percentage) from 1991 to 2002 for colorectal and breast cancer<sup>3</sup>**



- **More cancers detected through screening**
  - the breast screening programme has been extended to encompass all women aged 50 to 70 years. Between 2000 and 2005 the number of new cancers diagnosed through breast screening increased by over 60%. A national bowel cancer screening programme has also been launched and is the first screening programme to target both men and women. Between the start of the roll out in April 2006 and October 2007, over 400 cancers have been detected, out of 305,000 returned kits;
- **Faster diagnosis and treatment** – waiting times for cancer care have reduced dramatically:
  - Over 99% of patients referred urgently by their GP with a suspicion of cancer are now seen within two weeks (compared with 63% in 1997);
- More than 99% of patients now receive their first treatment for cancer within one month of diagnosis (in 1999/2000 only 31% of patients surveyed reported that they received their first treatment within a month of their first hospital appointment<sup>5</sup>); and
- Almost 97% of urgently referred patients who are subsequently diagnosed with cancer start their treatment within two months of referral, compared with 75% as recently as 2004.
- **Improved access to better treatments** – there has been a major increase in the use of drugs to treat cancer which have been approved by the National Institute for Health and Clinical Excellence (NICE), with less variation in their usage between cancer networks.

Figure 4: Comparisons of cancer mortality in Europe in 2006<sup>4</sup>





1.7 These improvements have been supported by significant additional investment. Estimates indicate that cancer services received an extra £639 million of funding between 2000/01 and 2003/04, exceeding the NHS Cancer Plan objective of £570 million. In total, approximately £4.35 billion was spent on cancer services in 2006/07, amounting to 5.2% of all NHS spending.<sup>6</sup> This spending has helped to improve the quality and capacity of cancer services. For example:

- Unprecedented numbers of new CT scanners, MRI scanners and Linear accelerators have been installed;
- Major cancer centre developments are underway (in, for example, Leeds, Hull, Oxford, Newcastle, Southampton and Taunton and Somerset);

- New clinical nurse specialist posts have been established, improving the delivery of information, support and care to patients;
- Support for specialist palliative care and hospices has been enhanced; and
- The cancer workforce has expanded significantly (see Figure 5).

1.8 The cancer nursing workforce has also grown. Recent analysis shows that there are currently approximately 2,000 Clinical Nurse Specialists (CNSs) related to individual cancer sites, which excludes nurses working in chemotherapy and palliative care. Figures are not available for 2000, but this undoubtedly represents considerable expansion.

**Figure 5: The expanding cancer workforce**

Headcount			Percentage	Projected	
	2000	2006	increase 2000-2006	2012	percentage increase 2006-12
<b>Consultants in Selected Specialties with a Major Role in Cancer Care</b>	<b>9,681</b>	<b>13,137</b>	<b>36</b>	<b>17,852</b>	<b>36</b>
– General Surgery	1,331	1,756	32	2,387	36
– Urology	382	510	34	700	37
– Anaesthetics (inc. intensive care)	3,322	4,698	41	6,464	38
– Respiratory medicine	439	583	33	815	40
– Gastroenterology	481	639	33	985	54
– Clinical Radiology	1,585	2,061	30	2,320	13
– Histopathology	865	1,087	26	1,611	48
– Clinical Oncology	307	482	57	636	32
– Medical Oncology	133	233	75	395	70
– Palliative Medicine	111	185	67	402	117
– Haematology	527	663	26	804	21
– Cardiothoracic Surgery	198	240	21	333	39
<b>All radiographers</b>	<b>12,489</b>	<b>14,564</b>	<b>17</b>	<b>17,585</b>	<b>21</b>
– Diagnostic Radiographers	11,036	12,535	14	14,605	17
– Therapeutic Radiographers	1,453	2,029	40	2,980	47

1.9 This investment has been accompanied by radical reform the way that cancer services and cancer research are organised:

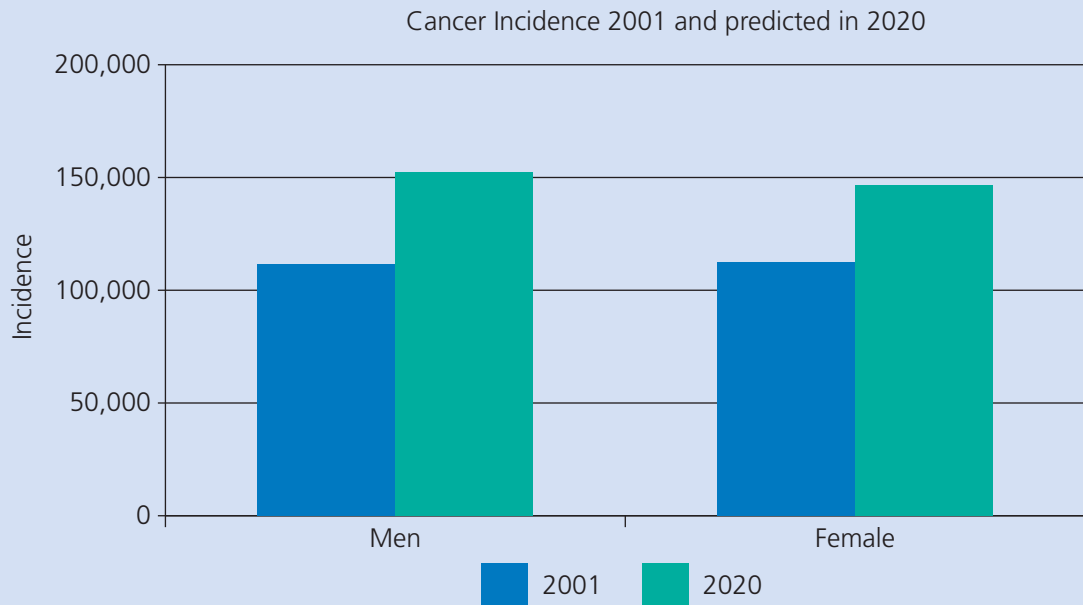
- Around 1,500 Multi Disciplinary Teams for cancer have been established in line with improving outcomes guidance produced initially by the Department of Health and more recently by NICE;
- Services are being redesigned so that complex surgery is performed only by specialist teams, in line with NICE guidance;
- Thirty cancer networks coordinate services for patients across all aspects of care and increase collaboration across organisational boundaries;
- The National Cancer Research Institute (NCRI) has been established, bringing together major research funders and ensuring strategic co-ordination of the nation's cancer research efforts; and
- Cancer research networks have been established to increase recruitment of patients into cancer clinical trials. In the last five years, this has led to the tripling of the number of cancer patients entering trials and in each of the last two years England has had the highest national per capita rate of cancer trial participation in the world.

1.10 As a result of clear vision, investment, reform, new technologies and treatments and not least the hard work and dedication of thousands of individuals, we have made significant progress against cancer.<sup>7</sup> This assessment is supported by the government's independent spending watchdog, the National Audit Office, which in 2005 concluded that "substantial progress has been made to date, with many targets in the plan met or on course to be met".<sup>8</sup>

### Looking forward

1.11 While the outlook for cancer has been transformed over the past decade, major challenges remain:

- The incidence of cancer continues to rise due to the ageing population and is predicted to increase by around a third between 2001 and 2020 (see Figure 6);
- The link between obesity and cancer is now much clearer than it was seven years ago and the substantial rise in levels of obesity will further increase the numbers of new cancers;
- Major inequalities in cancer death rates between rich and poor remain;
- Survival rates for some poor prognosis cancers have remained largely unchanged, such as for lung cancer and pancreatic cancer, partly due to difficulties in diagnosing these cancers early;
- Advances in medical technology are creating major new opportunities to diagnose and treat cancer more effectively but these will place additional cost and capacity pressures on services (see Box 1);
- The NHS Cancer Plan was a ten year plan and the work started by it needs to be completed and sustained, for example on service reconfiguration;
- An 'information deficit' remains which inhibits patient care management and limits the ability of patients to make informed choices on treatment and services; and
- More people are now surviving cancer or living with it for many years. They may require different kinds of care and support from those traditionally available.

**Figure 6: Trends in Cancer Incidence<sup>9</sup>**

#### Box 1: Advances in medical technology for cancer

- New techniques such as liquid-based cytology and regular use of two-view mammography are allowing more accurate and earlier diagnosis;
- PET-CT scanning enables more accurate staging of cancer, ensuring the most appropriate treatment can be given;
- Minimally invasive surgery techniques are reducing complications and enabling patients to make a faster recovery;
- Better radiotherapy means that higher doses of radiation can be more accurately and safely delivered, improving outcomes and reducing side effects; and
- New targeted therapies are providing different ways of treating cancer and with more than 50% of all new drugs in development being aimed at cancer, further advances can be expected.

#### Aims of the Cancer Reform Strategy

**1.12** In order to build on the progress already made and meet the challenges that remain, the government has developed this Cancer Reform Strategy to set out the next steps for delivering cancer services in England.

**1.13** During the 1990s, survival rates improved in England but we did not close the gap with the best European countries. By 2012 our cancer services can and should become not only among the best in Europe but among the best in the world. This is the aspiration that drives this Cancer Reform Strategy.

**1.14** In order to compare our services to others worldwide, we will collaborate with partners in Europe and in other countries such as Australia, New Zealand, Canada and the USA to share data and assess our performance.

**1.15** To achieve this aspiration, the Cancer Reform Strategy (CRS) aims to:

- Save more lives – through prevention of cancer whenever possible and through earlier detection and better treatment;

- Improve patients' quality of life – by ensuring that services are patient-centred and well coordinated and by offering choice where this is appropriate;
- Reduce inequalities in public awareness of cancer, in access to services and in service quality – thereby reducing inequalities in cancer outcomes;
- Build for the future, through education, research and workforce development;
- Achieve maximum value for money for the tax payer and the NHS, by ensuring that resources are directed where they will yield the most benefit; and
- Enable cancer care to be delivered in the best place, at the right time.

1.16 This strategy takes account of the challenges related to cancer and the likely developments in society up to and beyond 2020. Major developments in scientific understanding can be expected over this period but it is difficult to predict which developments will impact on clinical practice in 13 years' time. The strategy therefore focuses particularly on the actions that are needed now and over the next five years to maintain and build on recent progress.

1.17 The major strategic themes can be set out under two headings: firstly, areas of action needed to improve cancer outcomes; and secondly, areas of action needed to ensure delivery.

1.18 The six areas where action is needed to improve cancer outcomes are:

- **Prevention** – over half of all cases of cancer could be prevented through changes to lifestyle such as quitting smoking, maintaining a healthy weight and avoiding excessive alcohol consumption, but public awareness of many of these and other risk factors is low;

- **Earlier diagnosis and treatment** – if we can diagnose more cancers early we can have a significant impact on survival rates. Enhancing cancer screening, improving public awareness of cancer symptoms and going further on cancer waits will help to achieve this;
- **Ensuring access to cost effective treatments** – we need to tackle the serious shortage of radiotherapy capacity and there are concerns about delays in our uptake of new cancer drugs. We also need to encourage the spread of improved surgical techniques;
- **Improving patients' experience** – a higher priority should be placed on improving information for patients, face-to-face communication with health professionals and co-ordination and continuity of care. We also need to do more to support patients throughout their survivorship;
- **Reducing cancer inequalities** – we can tackle inequalities in the experience and outcomes of different groups in society through better data collection, research and spreading good practice; and
- **Delivering care in the most appropriate setting** – we can achieve the quickest possible diagnoses and reduce unnecessary stays in hospital with new service models for cancer.

1.19 The four areas of action needed to ensure delivery are:

- **Better information** – improved collection and publication of data on clinical outcomes for cancer will improve service quality and strengthen commissioning and is a prerequisite for informed choice for patients. We also need to gather more information on public awareness of cancer risk factors and symptoms and on patients' experiences of cancer care;

- **Stronger commissioning** – this strategy is designed to support commissioners in planning and providing high quality cancer services which reflect the needs of the local population;
- **Appropriate funding** – appropriate funding will be provided to build world class cancer services but commissioners will need to ensure that money is well spent; and
- **Building for the future** – we need to build on the progress we have seen in cancer research in recent years, including developing a new national repository of cancer data and enhancing research efforts in areas where knowledge is lacking. We also need good planning to provide a skilled and flexible cancer workforce for the future and to deliver high-quality facilities and environments for cancer care.

1.20 This strategy has been developed in parallel with an End of Life Care Strategy, covering cancer and other conditions, which is anticipated to be published in parallel with the final report of the NHS Next Stage Review. To avoid duplication only those aspects of end of life care which are specific to cancer are covered in this strategy.

## Development of the strategy

1.21 Large numbers of individuals and organisations have been involved in the development of the Strategy. These include:

- Members of the Advisory Board and Working Groups;
  - Clinicians and managers working throughout the NHS;
  - Patients, including through a workshop specifically for service users;
  - Social care representatives;
  - Cancer charities; and
  - Healthcare industry organisations.
- 1.22 Many groups have devoted a great deal of constructive thought to how cancer policy should develop to address the challenges outlined above. For example:
- We asked groups of experts, consisting of healthcare professionals, researchers and patient representatives, to develop realistic visions of how they believe services for particular cancers could develop by 2012 (see Box 2);
  - Existing Department of Health advisory groups on lung cancer & mesothelioma, bowel cancer, prostate cancer and children & young people with cancer met to discuss their visions for cancer in 2012;
  - The Cancer Campaigning Group, a coalition of over 30 national cancer charities, published a report *Getting it right for people with cancer: What the voluntary sector wants from the Cancer Reform Strategy*, setting out some key principles on which future policy should be developed (see Box 3);
  - Cancer Research UK has developed its 2020 goals (see Box 4);
  - Cancer 52, an alliance of charities which support people with less common cancers, has come together to consider what steps need to be taken to improve outcomes for these cancers;
  - The All-Party Parliamentary Group on Cancer published its 'New Vision for Cancer';
  - Tumour-specific coalitions, such as the Prostate Cancer Charter for Action and the United Kingdom Lung Cancer Coalition have identified areas for prioritisation in tackling specific cancers;
  - The Academy of Medical Royal Colleges formed the Inter-Collegiate Cancer Committee to provide health professionals' perspectives on cancer policy;
  - The NCRI has consulted widely on cancer research needs and opportunities;

**Box 2: Visions for 2012**

Bowel cancer	Head, neck and thyroid cancers
Brain and central nervous system cancers	Lung cancer and mesothelioma
Breast cancer	Prostate cancer
Cancer genetics	Sarcoma
Cancer screening	Skin cancers
Children and young people and cancer	Upper gastrointestinal cancers
Gynaecological cancers	Urological (excluding prostate) cancers
Haematological cancers	

- The Pharmaceutical Oncology Industry Partnership has been formed to consider how best industry should support the NHS in tackling cancer; and
- A report on cancer was produced by a group representing independent sector providers.

**1.23** The Department of Health welcomes these goals and principles. Cancer Research UK's 2020 Goals are rightly challenging (see Box 4), but are achievable provided that further action is taken now by all partners involved in cancer. We will therefore be informed by these goals and principles as we implement the Cancer Reform Strategy.

**Cancer in a reformed NHS**

**1.24** Cancer services now operate in a very different environment from when the NHS Cancer Plan was developed in 1999/2000:

- NHS structures have changed and greater authority has been devolved to local organisations, with over 90% of all NHS funding being with PCT commissioners;
- Greater patient involvement is changing the way in which decisions about treatment are made;

**Box 3: Cancer Campaigning Group Key Principles from 'Getting it right for people with cancer: What the voluntary sector wants from the Cancer Reform Strategy'**

1. Continued national leadership is essential to tackle a disease that affects us all;
2. Greater efforts should be made to prevent cancer and to raise awareness of the disease in order to save and improve more lives and make best use of resources;
3. Every person affected by cancer deserves high quality care, treatment, information and support, regardless of location, gender, ethnicity, age, financial status, literacy, religion, sexual orientation, disability or type of cancer;
4. People with cancer and their carers should have the opportunity to be equal partners in decisions about their treatment and care;
5. Cancer services should treat the person, not just the tumour, throughout the cancer journey;
6. Policies should promote and support all aspects of cancer research, as the foundation for high quality cancer services; and
7. Resources should be allocated to ensure those cancers where progress has been slower can catch up with those where the most significant improvements have been delivered.

#### Box 4: Cancer Research UK 2020 Goals

Cancer Research UK has developed ten goals to measure success over the coming years in beating cancer. Cancer Research UK will work with partners to achieve the following by 2020:

1. **People will know how to reduce their risk of cancer** – Three quarters of the UK public will be aware of the main lifestyle choices they can make to reduce their risk of getting cancer;
2. **The number of smokers will fall dramatically** – Four million fewer adults will be smokers, preventing thousands of new cases of cancer every year;
3. **People under 75 will be less likely to get cancer** – The chances of a person developing cancer up to the age of 75 will fall from more than one in four to one in five;
4. **Cancer will be diagnosed earlier** – Two-thirds of all cancer cases will be diagnosed at a stage when the cancer can be successfully treated;
5. **We will understand how cancer starts and develops** – We will have a detailed understanding of the causes and changes in the body in two-thirds of all cases of cancer;
6. **There will be better treatments with fewer side effects** – Treatments that accurately target the cancer and have few serious side effects will be available for at least half of all patients;
7. **More people will survive cancer** – Survival rates for all common cancers will increase, with more than two-thirds of newly-diagnosed patients living for at least five years;
8. **We will especially tackle cancer in low income communities** – The differences in the risk of dying from cancer between the most affluent and the least affluent will be reduced by half;
9. **People with cancer will get the information they need** – At least nine out of ten patients will be able to access the information they need at the time of diagnosis and during treatment; and
10. **We will continue to fight cancer beyond 2020** – Sufficient scientists, doctors, nurses and infrastructure will be in place to ensure continued rapid progress in the fight against cancer beyond 2020.

- Following record increases in investment in the NHS, the rate of growth in spending is set to slow to a four percent real increase per year, taking total expenditure on the NHS to £110 billion by 2010/11;
  - There is a greater focus on delivering value for money through improving efficiency within the service and from new delivery models; and
  - Cancer has a higher public profile than ever before and the improvements in cancer care have rightly raised patient expectations still further.
- 1.25 The initial priority for cancer services in the NHS Cancer Plan was to increase capacity through investment in the workforce and in facilities. The first stages of reform were also introduced, driven in part through national targets and commitments, for example on waiting times and through centrally managed budgets, such as for capital equipment programmes and for specialist palliative care.
- 1.26 National direction has come from:
- Publishing the NHS Cancer Plan, the first national comprehensive plan for cancer, setting out the strategic direction for cancer services across the country;

- The work of the National Cancer Director, with support from the Department of Health Cancer Policy Team, the Cancer Action Team, the Cancer Services Collaborative Improvement Partnership and NHS Cancer Screening Programmes, in championing service quality and change;
- Developing evidence-based guidance to support local services;
- National measures against which all services are assessed through peer review; and
- Coordination of cancer research through the NCRI and the National Cancer Research Network (NCRN).

1.27 Local implementation has been achieved through:

- Cancer networks bringing together all the key local organisations – Primary Care Trusts, NHS Trusts and the voluntary sector – and individuals such as clinicians, managers and service users to plan and monitor service delivery;
- Establishing multidisciplinary teams (MDTs) to bring together the relevant expertise to help plan care for individual patients;
- Focused service improvement resources invested in service redesign at the frontline; and
- Local research networks with dedicated funding.

1.28 Other stakeholders have also contributed very significantly to progress on cancer. These have included cancer charities, the pharmaceutical industry and other government departments. Partnerships have been established to:

- Promote research through the National Cancer Research Institute and National Cancer Research Network;
- Develop new models of service such as pilots for genetics services;

- Deliver better information to patients;
- Enhance training, such as for district nurses in to palliative care and for GPs in cancer;
- Improve planning of chemotherapy services; and
- Ensure the voice of patients is heard through user partnership groups in each cancer network.

1.29 Looking forward, that mix of some national direction, effective local implementation and working in partnership remains the broad approach needed to deliver further improvements in cancer services. However, the Cancer Reform Strategy reflects the change in balance between national and local control in the NHS. Continued national direction will be provided in certain areas, such as the successful standards for cancer waiting times and the national cancer screening programmes. However the overall focus of the strategy is on enhancing local delivery, by giving advice and support to commissioners and providing incentives for the providers of NHS care at a local level to deliver high quality, cost-effective care for cancer patients.

1.30 A range of levers is now available to incentivise local service improvement. These include:

- National guidance to inform local needs;
- Information and research evidence;
- A stronger patient voice and more patient choice;
- Stronger commissioning;
- Plurality of service provision;
- National tariffs;
- Standards and regulation; and
- Nationally defined contracts for local service arrangements determined by commissioners.



1.31 Each of these levers will be employed to drive the multiple improvements in cancer services set out in this Cancer Reform Strategy. Subsequent chapters show how the different levers will be applied to tackle different challenges.

1.32 Significant further investment will be needed to deliver the world class cancer services we aim to achieve. Overall costs of cancer are set to rise with increasing incidence and more effective treatments. We need to invest more in prevention and early detection. But there is also potential to improve efficiency and thereby release resources, especially in relation to inpatient care. Chapter 10 sets out these funding issues in more detail.

### Cancer and the NHS Next Stage Review

1.33 A major review of the way the NHS delivers patient care is underway ahead of its 60th anniversary in 2008. Led by health minister Lord Darzi, the NHS Next Stage Review will identify the way forward for a 21st century NHS which is clinically-driven, patient-centred and responsive to local communities.<sup>10</sup>

1.34 The current stage of the review has brought together clinicians from across the country to focus on eight clinical pathways representing the various stages in a person's life where they may encounter health and social care. These are: maternity and newborn; children's health; staying healthy; long term conditions; acute care; planned care; mental health and end of life care.

1.35 With the possible exception of maternity and newborn care, cancer is an important part of all of the clinical pathways being considered. Key findings and recommendations from the Cancer Reform Strategy will feed into the work currently underway at both the national and Strategic Health Authority level as part of the NHS Next Stage Review. While recommendations throughout the strategy can inform the review, the moves set out in chapter 7 for delivering cancer services in the most appropriate settings are most directly relevant.



# **Part 2:**

# **The next steps for cancer**



## Chapter 2: Preventing cancer

### Chapter Summary

- Over half of all cancers are potentially preventable, with smoking being the single largest preventable cause of death;
- The fall in smoking prevalence over the past decade is attributable in part to the introduction of a comprehensive tobacco strategy;
- The introduction of smokefree legislation should be seen as a launch pad for further action. The government will consult on further initiatives in Spring 2008;
- Obesity is now the most important preventable risk factor for cancer in non-smokers. A cross-government strategy to tackle cancer will be published shortly;
- The incidence of skin cancers is rising. The government will increase funding to raise awareness of the dangers of over exposure to sunlight and is considering the need for regulation of the sunbed industry;
- Vaccination to prevent cervical cancer will start in 2008; and
- New initiatives to strengthen research into prevention of cancer are underway.

### Introduction

2.1 Over half of all cancers could be prevented if people adopted healthy lifestyles such as<sup>11</sup>:

- Stopping smoking;
- Avoiding obesity;
- Eating a healthy diet;
- Undertaking a moderate level of physical activity;
- Avoiding an excessive alcohol intake; and
- Avoiding excessive exposure to sunlight.

2.2 Action to increase awareness of these risk factors and encourage people to adopt healthy

lifestyles is therefore a crucial part of the government's strategy to tackle cancer.

2.3 Vaccination now presents a further opportunity in cancer prevention, specifically for cervical cancer. As announced in October 2007, the government is introducing a national vaccination programme for young girls against the human papillomavirus. This will protect against the strains of the virus which cause around seven out of ten cases of cervical cancer. It is hoped that the vaccination programme will save around 400 lives a year.

### Awareness of the risk factors for cancer

2.4 Public awareness of the main preventable risk factors for cancer is poor. A recent survey undertaken by Cancer Research UK's Reduce the

Risk campaign showed that only five percent of the population could, unprompted, name four of the six lifestyle factors linked to cancer listed above. Seventy seven percent were only able to name two or fewer of these factors.

2.5 Awareness of risk factors for cancer is particularly low in deprived groups.<sup>12</sup>

2.6 We need to do more to raise public awareness of the risk factors for cancer. Cancer Research UK is funding the development of a modular tool to assess levels of awareness of cancer risk factors and symptoms. This tool will enable the monitoring of changes in awareness levels over time, which will help in evaluating the success of interventions designed to increase awareness and encourage behaviour change. The tool is expected to be available in 2008.

## Role of Primary Care Trusts in cancer prevention

2.7 As set out in the Local Government and Public Involvement in Health Act (and the subsequent draft statutory guidance 'Creating strong, safe and prosperous communities') Primary Care Trusts (PCTs) and local authorities will have a duty to undertake a Joint Strategic Needs Assessment of the current and future health and social care needs of their population. The Department of Health will shortly be issuing guidance on this duty.

2.8 Joint Strategic Needs Assessment will lead to *shared* priorities for commissioning to improve outcomes and reduce health inequalities. These priorities will be used to inform the Sustainable Communities Strategy and targets within the Local Area Agreement.

**2.9 Given the importance of cancer prevention, PCTs and cancer networks should give high priority to increasing awareness of risk factors. They may wish to use the risk factor module of Cancer Research UK's forthcoming assessment tool to define a baseline and assess progress.**

2.10 The lifestyle factors known to increase risk of cancer also, with the exception of excessive exposure to sunlight, increase risk of other conditions including coronary heart disease,

stroke, diabetes and chronic obstructive pulmonary disease. PCTs and local partners may therefore wish to tackle these challenges collectively.

2.11 There are a number of existing initiatives which present opportunities to improve awareness of the risk factors for cancer and encourage individual action to address them. These include the work of health trainers, the NHS Life Check programme and the information provided on the NHS Choices website.

## Tobacco and Cancer

2.12 Smoking is the single largest preventable cause of death from cancer, accounting for around one third of all cancer deaths and up to 90% of lung cancer cases.

2.13 Differences in smoking rates between the most and least affluent groups in society account for around half of the inequalities gap in cancer mortality between these groups.

2.14 Much of the improvement in cancer death rates over the past 20-30 years can be attributed to reductions in smoking amongst adults. Smoking prevalence amongst adults has continued to fall over the past decade. This has been achieved in part due to the introduction of a comprehensive anti-tobacco strategy. Recently government action has included:

- Action on smuggling and illicitly traded tobacco;
- A comprehensive ban on tobacco advertising;
- New hard-hitting picture warnings on all tobacco packaging from October 2008;
- Education and communications campaigns on smoking run by the government (including those by health charities run in partnership with the Department of Health); and
- Funding to ensure that local stop smoking services can be provided by all PCTs in England.

**2.15** The new smokefree law in England, which has been effective since 1 July 2007, has been described as the single most important public health initiative for a generation. The new smokefree law will provide protection for everyone in virtually all enclosed workplaces and public places from the harmful effects of second hand smoke.

**2.16** Second hand smoke is a serious health hazard and there is no safe level of exposure. Scientific evidence shows that exposure to second hand smoke increases the risk of serious medical conditions such as lung cancer, heart disease, asthma attacks and sudden infant death syndrome. While the law in England is still in its early days, we already know that:

- Support for a Smokefree England is strong, with over three-quarters of people in support of the new law. More smokers support the law than oppose it;
- Smokefree legislation is well respected with over 98% of smokefree premises and vehicles inspected by local authorities across England in August being properly compliant; and
- Researchers have found that, since smokefree legislation was introduced in Scotland in March 2006, there has been a dramatic improvement in air quality in pubs; no increase in smoking in the home and reduced tobacco consumption, particularly in disadvantaged communities.

**2.17** In October 2007, the age of purchase of cigarettes was raised from 16 to 18. We believe that this increase in the age of sale for tobacco, with recently announced legislative proposals for tougher sanctions against retailers who break the law, will help to reduce the availability of cigarettes to young people. It will also help to communicate the serious health risks associated with smoking and contribute to a further reduction in the numbers of young people who take up smoking in the first place.

**2.18** However, the tobacco epidemic is not yet over. We must see the implementation of smokefree legislation as the launch pad to take further action to tackle smoking in this country. Tobacco control policy must remain a priority, both nationally and locally. Smoking rates remain comparatively high in routine and manual workers and in the north of England and smoking prevalence is particularly high in some very deprived groups. Eighteen percent of men and 16% of women in the professional and managerial groups smoke compared with 32% of men and 29% of women in routine and manual groups (2005 figures).

**2.19** Around seven in ten smokers say they want to quit smoking. Smokers who quit with the support of the NHS are significantly more likely to succeed than those who do not make use of NHS support. In the six years since 2000, the number of smokers who have used the support available from the NHS stop smoking services has increased by over 350%. We will continue to make every effort to encourage smokers to quit with the support of the NHS into the future.

**2.20** The government runs highly effective stop smoking campaigns to motivate and support smokers to stop and particularly to encourage them to use NHS support when quitting, so increasing their chances of doing so successfully. So far this year, over a million people have responded to the campaign via the NHS Smoking Helpline, [www.gosmokefree.co.uk](http://www.gosmokefree.co.uk) website and interactive TV, to ask for support to stop smoking.

**2.21** The government is currently proposing new prohibition orders for retailers who sell to underage children. These new measures adequately reflect the seriousness of selling tobacco to underage children. Access to cigarettes by under 16 year olds has not been as difficult as it should be – less than a quarter of 11-15 year olds who have tried to buy cigarettes from small shops have found it difficult to do so. Those who repeatedly flout the law and sell tobacco to children should not be allowed to continue to sell a harmful and addictive product such as tobacco.

2.22 Hard-hitting picture warnings will appear on all tobacco products produced for the UK market from 1 October 2008. There is considerable research that demonstrates the benefits of introducing pictorial warnings from countries such as Canada and Australia where they have had picture warnings for some years. Smokers there are more likely to act on the warnings that are on tobacco packs if they are in picture form.

**2.23 Further coordinated action on tobacco remains central to the government's strategy to tackle cancer and smoking related diseases, to reduce health inequality and to promote public health. During Spring 2008, the government will consult on proposals for the next steps in tobacco control and the further regulation of tobacco products, including the display of tobacco at the point of sale, access to tobacco from vending machines and packaging.**

2.24 In addition, the government is committed to action in the following areas of tobacco control:

- **Taxation on tobacco products:** The government recognises that the price of tobacco products is one of the most important factors in determining consumption. The UK has the highest priced cigarettes in the EU and the government continues to follow a policy of using tax to maintain the high price of tobacco at levels that will impact on smoking prevalence;
- **Tackling the major problem of illicit tobacco:** A continuing increase in the availability of cheaper, illegally smuggled cigarettes and hand rolling tobacco would mean that many smokers are able to bypass higher prices, undermining the impact of price on smoking prevalence rates and reducing the value of tax increases in reducing smoking prevalence. The government will continue to work with stakeholders to tackle the availability of illicit tobacco in our communities. The government is also committed to working with international partners to develop a global protocol on illicit tobacco, under the Framework Convention on Tobacco Control;
- **Reducing the harm to smokers who cannot quit:** Smoking is powerfully addictive and is an extremely dangerous way to get nicotine. Cigarette smoke contains over 4,000 chemicals including known carcinogenic agents and smoking is positively associated with over 40 diseases. While recognising that it is crucial to continue to support smokers to quit smoking, the government will consult with stakeholders on measures to reduce the significant harm to health caused by smoking for those who are addicted to nicotine and not able to quit altogether; and
- **Social marketing initiatives:** The government will continue to invest in social marketing initiatives at the national level to support people to stop smoking, especially with the free support available from the NHS. Social marketing initiatives will be focused towards groups in our community with the greatest smoking prevalence.



### Nicotine replacement therapy

2.25 We want more people to quit smoking and to have as much support as possible to do this easily. Many PCTs commission community pharmacies to provide one to one NHS stop smoking services, which have helped many people quit smoking.

2.26 Our aim is to widen access to Nicotine Replacement Therapy (NRT) products to support smokers to quit. By making NRT available on prescription, widen the license for NRT products, allowing NRT to be available for sale as a General Sales List product as well as allowing qualified independent pharmacists and nurse prescribers to prescribe NRT, the government has made significant achievements in this area.

**In addition, some PCTs have enabled pharmacists to supply NRT through voucher schemes or Patient Group Directions, to support and simplify access to NRT. We are keen to see this practice adopted more widely so that more smokers can quit, benefiting their overall health.**

### Obesity, Diet and Physical Activity

2.27 The evidence linking obesity to cancer has become much stronger since the publication of the NHS Cancer Plan in 2000.<sup>13</sup> Being obese increases the risk of many cancers, especially cancers of the uterus, kidney, colon, gallbladder and oesophagus. It is also linked to breast cancer in post-menopausal women.

2.28 For non-smokers, obesity is now the most important preventable risk factor for cancer. Action to prevent obesity is therefore essential to the Cancer Reform Strategy's aim to prevent more cancers.

2.29 In October 2007, the government's Foresight research programme published its report on obesity and its modelling suggests that 60% of men, 50% of women and about 25% of all children under 16 could be obese by 2050. The report argues that, although personal responsibility plays a crucial part in weight gain, human biology is being overwhelmed by the effects of today's 'obesogenic' environment, with its abundance of energy-dense food, motorised transport and sedentary lifestyles.

The Foresight report recommends whole societal change with cross governmental action and that a long term commitment is required to tackle the obesity epidemic.<sup>14</sup>

2.30 Also in October 2007, the World Cancer Research Fund published a report, 'Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective'.<sup>15</sup> This provides a comprehensive scientific review of the evidence and presents a set of policy and personal recommendations for the prevention of cancer. Box 5 below gives a summary of the report's recommendations.

2.31 A further recent study has quantified the number of cases of cancer in women caused by obesity and overweight.<sup>16</sup> The Million Women Study, funded by Cancer Research UK, is the biggest study ever undertaken to look at women and cancer risk. Over one million UK women were studied during seven years. The study has found that among middle aged and older women in the UK, around five percent of all cancers, or 6,000 cancers each year, are caused by being overweight or obese. Two thirds of the additional 6,000 cancers each year due to overweight or obesity are cancers of the womb or breast.

2.32 The government has launched a number of programmes, many of which are demonstrating some success:

- Tough new nutritional standards in schools are now in place;
- 86% of school children now do at least two hours of quality school sport a week, beating the government target of 85% by 2008;
- We have worked with the Food Standards Agency to introduce a traffic light system for front-of-pack labelling on foods, making it simpler for consumers to make healthier food choices;
- We have, with the communications industry regulator OFCOM, placed restrictions on food and drink advertising to children; and

### Box 5: Recommendations for cancer prevention from the World Cancer Research Fund report 'Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective'

- Be as lean as possible within the normal range of body weight;
- Be physically active as part of everyday life;
- Limit consumption of energy-dense foods;
- Avoid sugary drinks;
- Eat mostly foods of plant origin;
- Limit intake of red meat and avoid processed meat;
- Limit alcoholic drinks;
- Limit consumption of salt;
- Avoid mouldy cereals (grains) or pulses (legumes);
- Aim to meet nutritional needs through diet alone rather than through supplements;
- Breastfeed children; and
- Cancer survivors are advised to follow the recommendations for cancer prevention.

- The Department for Communities and Local Government has a range of programmes that support tackling obesity by aiming to create safe, clean environments which encourage activity and many local neighbourhood renewal projects are focusing on improving access to healthy food.

**2.33 The government has committed to developing a cross-government strategy to tackle obesity. In October 2007 as part of the Comprehensive Spending Review a new cross-departmental child health Public Service Agreement was set out. The target is to reduce the rate of increase in obesity in children under eleven years old, in the context of a long-term ambition to reduce, by 2020, the proportion of overweight and obese children to 2000 levels.**

## Alcohol

**2.34** Excessive alcohol consumption is strongly linked to an increased risk of several cancers, including mouth, larynx, oesophagus, liver and breast. Combining excessive alcohol consumption with smoking further increases cancer risk.

**2.35** 'Safe, Sensible, Social – Next Steps in the National Alcohol Strategy', launched on 5 June 2007, aims to reduce the types of harm that are of most concern to the public (crime and ill-health) and increase the public's awareness of the risks associated with excessive consumption and how to get help. Overall, it aims to:

- Increase the number of people drinking within sensible drinking guidelines;
- Reduce the number of men who are drinking more than 50 units a week and the number of women who are drinking more than 35 units or more than twice the sensible daily drinking guidelines on a regular basis;
- Reduce the number of under-18s who drink and the amount of alcohol they consume; and
- Shape an environment that actively promotes sensible drinking.

**2.36 A programme of activity is planned for next year and beyond to achieve this. It will include:**

- **A sustained national communications campaign will aim to raise the public's knowledge of units of alcohol and ensure everyone has the information they need to estimate how much they drink;**
- **Targeted information and advice for people who drink at harmful levels and their families and friends; and**
- **Consultation on the need for legislation regarding alcohol labelling.**

### Excessive Ultraviolet Exposure

2.37 Melanoma incidence is rising rapidly, such that it is one of the fastest growing types of cancer, almost certainly reflecting patterns of behaviour over recent decades. Although melanoma is more common in women than men, the death rate in men is higher at 2.7 per 100,000 compared to 1.9 per 100,000 (age standardised mortality rates).

2.38 The SunSmart campaign is a national campaign to promote behaviour change to

prevent skin cancer and raise awareness of the early signs of the disease. It is commissioned by the UK Health Departments and run by Cancer Research UK.

**2.39 Given the importance of prevention and early detection of skin cancer, the government is committed to increasing the funding available for awareness programmes.**

2.40 With incidence continuing to rise, further action is needed to prevent skin cancer. One concern is the use of cosmetic tanning salons (especially un-staffed salons), with the risks of excessive exposure by children and young people and lack of adequate information provided to customers about the health risks of using sunbeds.

2.41 The Sunbed Association, which represents around a quarter of the tanning salon industry, requires members to have staffed premises and adhere to a code of practice which prohibits use by under 16 year olds and requires the provision of information to their customers. In some areas, such as London and Birmingham, local licensing laws require certain standards and restrictions, but most of the country is not covered by such laws.

#### Box 6: The SunSmart Campaign

SunSmart's 2007 activities included:

- Providing tips to help holidaymakers avoid sunburn;
- Campaigning to raise awareness of the dangers of sunbeds;
- Providing information about skin cancer prevention for the public and professionals through the SunSmart website;
- Giving briefings to journalists to raise awareness of key skin cancer issues in the media;
- Supplying printed resources for professionals to use in local health promotion activities; and
- Helping schools to develop their own sun protection policies using SunSmart school policy guidelines.

There is clear evidence of SunSmart's successes to date. Since SunSmart's launch in 2003, the campaign has increased knowledge of the causes of skin cancer and the importance of early detection, increased awareness of actions that can be taken to prevent skin cancer, positively influenced attitudes to sun protection and promoted behaviour change among defined target groups.

2.42 Recently, both the World Health Organisation and the European Union have expressed their views that under 18 year olds should not use sunbeds.

2.43 The Health and Safety Executive provides guidance on its website for controlling health risks from the use of UV tanning equipment. Since the publication of the guidance in the mid-1990s there has been considerable technological change as well as an expansion in the sunbed industry. **The Department of Health is reviewing options for regulation of the industry and as a first step will gather more information about the number and distribution of sunbeds and the scale of sunbed use by minors. It is important that the Department of Health and the Health and Safety Executive, in consultation with other stakeholders including Cancer Research UK, consider ways in which a balance can be struck between consumer safety and choice.**

### Vaccination and cancer

2.44 Persistent infection with Human Papillomaviruses (HPV), a sexually transmitted virus that infects epithelial (skin) cells is necessary for cervical cancer to develop. However, most women are infected with HPV at some point and 90% clear it naturally. Furthermore, it is only some of those women with persistent HPV who go on to develop cervical disease. HPV infection is also associated with some other rarer anogenital cancers and cancers of the head and neck. Two HPV types HPV 16 and HPV 18 cause more than 70% of all cervical cancer cases. Vaccines are available to help protect against these two HPV types. To ensure maximum benefit and protection from this vaccine it is necessary to administer it before the onset of sexual activity.

2.45 In September 2008 an HPV immunisation programme will be introduced to routinely vaccinate girls 12-13 years of age, with a catch-up of girls up to age 18 years over the next two years starting in Autumn 2009. This decision follows the advice of the Joint Committee on Vaccination and Immunisation (JCVI) which carried out a detailed review of evidence

surrounding HPV vaccination. JCVI is an independent expert committee which advises on all immunisation issues to the Department of Health.

### Genetic predisposition and cancer

2.46 A person's risk of developing cancer is partly dependent on the genes they have inherited from their parents. A small proportion of common cancers is thought to be associated with faulty inherited genes. Those affected tend to develop cancer at a younger age than the general population and may therefore be not eligible for routine national screening programmes such as breast and bowel screening, which focus on older age groups. This section sets out how we will improve services for people with a strong family history or a known genetic predisposition to cancer. Surveillance of women found to be at high risk of developing breast cancer is discussed below.

2.47 The discovery of new genes and better understanding of the role of known genes associated with familial disposition, will in future allow better and earlier identification of those at risk of developing cancer through genetic tests. Research funders such as Cancer Research UK are making major investments in genetic epidemiology, with studies already funded in breast, bowel, lung, prostate and ovarian cancers.

2.48 The NHS Cancer Plan acknowledged that cancer genetic services were poorly developed. Patients were already seeking advice on whether they were at increased risk of developing cancer because of their family history, but primary care teams did not always have the information they needed to assess patients' risks.

2.49 In 2001, the Department began working with Macmillan Cancer Support to develop and pilot new services to assess genetic risk. The pilots provided risk assessment, information and counselling services in order to show that establishing dedicated family risk assessment and support services, coordinated across primary, secondary and tertiary care, can achieve seamless, effective and user-friendly services for those worried about a familial risk of cancer.

2.50 Seven pilot sites were established as part of the programme, each testing different models of delivering a cancer genetics service. Although the pilot sites operated their service in different ways for the benefit of their local populations, the core of each service consisted of the following:

- Promotion of the service;
- Access to the service (self- or primary care referral);
- Assessment of patients; and
- Classification of patients into high, moderate and general population risk, with clear pathways for each.

2.51 The range of service models explored included services targeted for specific ethnic minority populations, lower-socioeconomic groups and rural communities. They also involved a range of health professionals including primary care nurses, outreach genetics counselling from the genetics specialist service, GPs with special interests and cancer specialist nurses.

2.52 The pilots came to an end during 2007 and are being evaluated by a team at the University of Nottingham. If the pilots are shown to be effective, evidence based advice to the NHS will be developed on how best to set up and run familial genetics services. This advice will be closely linked with the full implementation of the NICE Familial Breast Cancer Guidance. Most of the pilot sites have already been successful in securing future funding to continue their service from local commissioners.

**2.53 We want people who are concerned about their family history of cancer to have access to cancer genetic services with high quality risk assessment and counselling services. Following evaluation, we will provide guidance to commissioners on how to commission these services.**

2.54 The 2003 Genetics White Paper announced an £18 million investment in technology for NHS genetics laboratories to improve the speed and accuracy of genetic testing.<sup>17</sup> Now that the new equipment is coming on stream, tests for cancer genes are being carried out more efficiently and most patients where the faulty gene in the family is known are not having to wait so long before knowing their result. Innovations in technology will make this testing even quicker and more accurate in future, but the complexity of these tests and what they mean still needs the availability of specialist genetic counsellors to prepare patients for testing and to explain the results.

### Research in cancer prevention

2.55 Several important initiatives are underway to strengthen research in cancer prevention and build an evidence base to inform policy and support the implementation of effective interventions to reduce cancer risk and encourage behaviour change.

2.56 Following the publication of a report in 2004, the National Cancer Research Institute brought a consortium of research funders together to set up the National Prevention Research Initiative (NPRI). The NPRI is a UK-wide initiative made up of government bodies, research councils and major medical charities that are working together to encourage and support research into chronic disease prevention, including cancer prevention. The NPRI is a multi-disciplinary initiative, managed by the Medical Research Council, which recognises that disease prevention is a major research priority.

2.57 NPRI funded studies are exploring a range of approaches to promoting positive health behaviour, to encourage people to avoid habits that increase their risk of cancer and to follow a healthy diet and physical activity programme. Many are taking place in local settings – schools, neighbourhoods, homes, the workplace and GP surgeries – with members of the community helping to develop and test new interventions. Some projects use the internet to influence health behaviour, develop partnerships with local food shops, train members of the

community to be health advisors, or use marketing communication skills to promote healthier living.

**2.58** The initial budget of twelve million pounds for NPRI will have been committed by early 2008 after two rounds of funding. NPRI partners have agreed to raise funds for a third and possibly future rounds and a wider range of participating organisations is anticipated.

**2.59** In response to the challenge of strengthening public health research and building on the work of the NPRI, the major funders of public health research have come together under the auspices of the UK Clinical Research Collaboration (UKCRC) and established a Public Health Research Strategic Planning Group. The aim of the group is to develop a coordinated approach to improving the public health research environment and it has identified that the most effective framework for this would be to fund a number of Public Health Research Centres of Excellence. Twenty million pounds has been provided by a consortium of funders including the Department of Health to provide infrastructure support to five such centres, which are likely to be operational in 2008. This initiative is managed by the Economic and Social Research Council.

## Chapter 3: Diagnosing cancer earlier

### Chapter Summary

- Late diagnosis has been a major factor contributing to poor cancer survival rates in the UK;
- The cervical screening programme will ensure that all women receive the results of their screening tests within two weeks by 2010;
- The age range for breast screening will be extended further to provide nine screening rounds between 47 and 73 years. Starting in 2008 this expansion will be completed by 2012. Direct digital mammography will be introduced over the same period;
- The NHS Bowel Screening programme will be extended from 2010 to invite men and women aged 70-75 years;
- The NHS Breast Screening programme will take responsibility for the management of surveillance for women at high familial risk of breast cancer;
- A new National Awareness and Early Diagnosis initiative will be established;
- Campaigns to raise awareness of the signs and symptoms of common cancers are being piloted in 20 deprived areas of the country; and
- A national audit in primary care of all patients newly diagnosed with cancer will be established.

### Introduction

**3.1** In general, the earlier a cancer can be diagnosed the greater the prospect of a cure. The later a cancer is diagnosed, the harder it is to treat and the poorer the patient's chances of survival. This is true for many cancers, including breast, colorectal, lung, ovary, oesophagus and stomach.

**3.2** Evidence suggests that later diagnosis of cancer has been a major factor in the poorer survival rates in the UK compared with some other countries in Europe.<sup>18</sup> Throughout the development of the Cancer Reform Strategy, experts and patients agreed that tackling late diagnosis is essential to improving outcomes for cancer patients. One of the priorities of

the strategy is therefore to diagnose more cancers early.

**3.3** To do this, we will:

- Extend and widen our existing screening programmes and continue to investigate opportunities for new screening programmes for other cancers;
- Raise public awareness of the signs and symptoms of early cancer and encourage people to seek help earlier, especially among groups where this awareness is particularly low; and

- Work with primary care professionals to ensure that patients presenting with possible cancer symptoms are appropriately investigated or referred to hospital without delay.

## Cancer screening

3.4 Currently national cancer screening programmes exist for breast, bowel and cervical cancer. We remain committed to introducing new screening programmes as and when they are proven to be both clinically and cost-effective.

3.5 Cancer screening in England is already highly advanced in comparison with that available in most countries and our programmes are renowned as being some of the best in the

world. We have high quality services and high levels of coverage. We routinely commission independent evaluations of screening pilot programmes and technologies. Some of the achievements of our three cancer screening programmes are set out below.

3.6 However, we now want to go further, saving more lives by further enhancing and expanding these programmes. The following sections set out what this will mean in practice.

## Improving cervical screening

3.7 Liquid based cytology (LBC) was recommended by the National Institute for Health and Clinical Excellence (NICE) in 2003 as the preferred technology for cervical screening.

### Box 7: Achievements in cervical screening

- The NHS Cervical Screening Programme saves up to 4,500 lives in England every year<sup>19</sup>;
- In 2006/07, 3.4 million women were screened and laboratories examined 3.7 million samples; and
- In 2006/07, over 40,000 women had high grade abnormalities detected and treated through the programme.

### Box 8: Achievements in breast screening

- The NHS Breast Screening Programme in England saves an estimated 1,400 lives per year. Screening now accounts for a third of all breast cancers detected;<sup>20</sup>
- There has been a 62% increase in breast cancers detected through screening in the past five years;
- Over 13,500 cancers were detected in 2005/06, of which 41% were small cancers less than 15mm which could not have been detected by hand; and
- 1.63 million women were screened in 2005/06.

### Box 9: Achievements in bowel screening

- The NHS Bowel Cancer Screening Programme is one of the first national bowel cancer screening programmes in the world;
- This is the first screening programme in England to invite men as well as women;
- The programme began in 2006 and full roll-out to all men and women aged 60 to 69 is expected by December 2009; and
- When fully rolled out, around two million men and women will be screened and around 3,000 cancers detected every year.



The main advantages of this new technique are a quicker throughput in laboratories and a large reduction in the number of samples that cannot be read. When fully implemented across England, this should mean that 300,000 women a year will not have to be re-tested due to unreadable samples, with all the anxiety that entails. This will also reduce the workload in laboratories.

3.8 Implementation of a NICE appraisal normally has to be funded by Primary Care Trusts (PCTs) within three months. At the time of the NICE appraisal of LBC, it was recognised that a major programme would be needed to retrain sample takers and laboratory staff who analyse the samples. A waiver was therefore issued by the Department of Health, recognising that full implementation within three months was not possible. By November 2007, 88% of laboratories in England had converted to LBC. The benefits of LBC are already becoming apparent. Of the four million tests taken each year, the number of inadequate tests fell from 370,000 (9%) in 2004/05 to 173,000 (4.7%) in 2006/07. This means that around 200,000 women did not have to attend for a repeat test, with all the anxiety that involves. All PCTs have indicated that they will have introduced LBC by October 2008 in line with NICE/DH guidance.

### 3.9 We now wish to see four further improvements in the cervical screening programme:

- **Reducing the variation of coverage between PCTs;**
- **Minimising the time taken to get results back to women, aiming to inform women of the result of their cervical screening test within two weeks of it being taken;**
- **Using new technologies, such as the automation of cytology reporting and the use of Human Papilloma Virus (HPV) testing as and when the research evidence supports this; and**

- **Action to tackle the falling participation of younger women aged 25 to 35.**

3.10 Nationally, 79.2% of eligible women were screened at least once in the last five years. But participation in cervical screening varies greatly across the country, from 86.5 % in Nottinghamshire County PCT to 67.4% in Hammersmith and Fulham PCT. Generally, participation is lower in spearhead PCTs than elsewhere, but there are examples of spearhead PCTs with high participation rates, such as Doncaster at 82%. Participation can be improved by engaging with potential users at a community level. **To incentivise services to encourage higher coverage we will explore moving to an activity based system for funding screening services. NHS Cancer Screening Programmes will also encourage the sharing of best practice in improving accessibility of screening for all groups.**

3.11 In September 2007, the government announced its intention to speed up the results of cervical screening, as set out in the manifesto for the 2005 general election. Women can expect to receive the results for their cervical screening test within 14 days of it being taken. The implementation of Liquid Based Cytology will go a long way to achieving this and we have already seen the number of women waiting more than six weeks for their results fall from 44% in 2005/06 to 27% in 2006/07. But we need to do more and further opportunities for improvements have been identified by formal options appraisals:

- Better use of Information Technology;
- More Advanced Biomedical Scientist Practitioners in Cervical Cytology;
- Posting results letters by first class mail;
- Reconfiguring laboratories to make them larger and more efficient; and
- Larger call/recall offices would also reduce turnaround times and allow better facilities to improve coverage such as telephone help lines.

**3.12 Local cervical screening services can achieve a two week turnaround time for results by adopting these measures. These turnaround times should be monitored locally and commissioners should intervene if the two week turnaround time is not being met. Turnaround times will also be monitored nationally via the Office for National Statistics / NHS Information Centre annual cervical screening statistical bulletin. The computer system will be amended to measure date of dispatch of the results letter and expected date of delivery.**

**3.13 Achieving two weeks from sample taking to the woman having her result will be a challenge for many parts of the country. It will involve all partners in the screening pathway, not just laboratories or Trusts. Local screening policies and arrangements may need fundamental change. The Cancer Services Collaborative Improvement Partnership will offer focused service improvement resources across the cervical screening pathway to support the delivery of faster turnaround times.**

**3.14 Advice to the NHS on achieving the two week turnaround time standard will be issued in early 2008. All women should receive the results of their cervical screening tests within two weeks by 2010.**

3.15 New technologies also have a part to play in modernising the cervical screening programme. Current research studies are looking at the use of automated cytology reporting, which will further improve turnaround times and put less strain on pathology staff and at the use of Human Papilloma Virus (HPV) testing as a primary screening tool. HPV testing as triage (sorting) for women with mild or borderline test results has also been piloted. Women with a mild or borderline screening result were tested for HPV and if HPV negative they were returned to the routine screening programme. Women who were HPV positive were referred to colposcopy. Following the initial trial, a number of sentinel sites will now begin HPV testing as triage. Results from these sites

will be known by 2009 at which point further roll out can be considered.

3.16 The NHS Cervical Screening Programme is likely to continue for many years after the introduction of the HPV vaccine. This is because the vaccines do not offer protection against all cancer causing HPV types and it will be a decade before the first girls vaccinated will be eligible for cervical screening. Screening will also still need to be offered to women up to the age of 65 who may have already been exposed to the virus. The Department of Health is considering commissioning further research to look at the implications for the screening programme.

3.17 In order to tackle the fall in coverage among younger women, NHS Cancer Screening Programmes have commissioned the Improvement Foundation to undertake work at a local level targeting this group. The lessons learned from this work, due in 2009, will be shared with SHAs and local screening programmes to develop best practice. The NHS Cancer Screening Programmes' press office is developing an information pack to be issued to all local screening programmes and also developing a public relations strategy, including articles in appropriate media publications, posters etc. In addition, Cancer Research UK have commissioned research on this issue, which we will monitor closely and will share the findings. Continued local action in this area is also essential and we will continue to monitor levels of cervical screening coverage through the ONS/Information Centre annual Cervical Screening Statistical Bulletin.

### Improving breast screening

3.18 Until 2000 routine invitations for breast screening were sent to women aged 50-64. Since then, the NHS Breast Screening Programme (NHSBSP) has been extended to increase the upper age to 70 and to include two-view mammography at each visit. As a result, the number of women attending for mammography has increased from 1.3 million in 2000/01 to 1.63 million in 2005/06 and the number of cancers detected has risen from 8,345 in 2000/01 to 13,523 in 2005/06. The two changes together resulted in a 40 percent

increase in the workload of the programme, which has only been possible because of new working practices and the dedication of screening staff (see chapter 11).

**3.19** Our first priority is to maintain this excellent record. To do this it is essential that the interval between screens (the round length) is maintained at three years. **PCTs will need to invest more in breast screening to ensure a three year round length because of increasing numbers of women from the 'baby boomer' generation becoming eligible for breast screening.** The National Cancer Director wrote to SHA Chief Executives in February 2007 alerting them to these challenges.

**3.20** We now want to extend the programme so that more women benefit and save even more lives. At present, women are invited for screening seven times at three yearly intervals between 50 and 70 years. **Over time, this will be extended to nine screening rounds between 47 and 73 years with a guarantee that women will have their first screening before the age of 50.** Over 400,000 more women will be screened each year as a result. Women over the eligible age range will be able to self refer for screening every three years, as at present.

**3.21 This extension of the breast screening programme will start from April 2008 and will be managed by NHS Cancer Screening Programmes in partnership with local health services. As with the previous extension (involving women 65 to 70 years) this will take several years to implement fully, as more staff will need to be recruited and trained and more equipment purchased. The necessary phasing in of this expansion will be carefully considered to ensure that the most useful epidemiological data can be gathered to inform future decisions about the programme. Full implementation is expected by the end of 2012.**

**3.22** An ICM poll commissioned by Breakthrough Breast Cancer in August 2007 revealed that 88% of women over 70 had not had any conversation with their GP about being

able to self-refer for screening every three years. A leaflet, developed in partnership with Age Concern and reminder cards, are available for women at their final invited screening appointment. Commissioners will wish to ensure that this information is routinely provided by their local screening service.

**3.23** Breast screening mammography is the last area of imaging in the NHS where film is still routinely used. There are several benefits to moving to digital mammography. It would allow the image to be manipulated so it improves the radiologist's ability to interpret breast tissue. Digital images could be exchanged electronically between radiologists at different hospitals to discuss difficult cases. Direct digital mammography has been shown to be more sensitive and specific for pre-menopausal women who have denser breasts. Finally, it also provides revenue savings in terms of reduced radiographer time and less chemicals or film handling and printing.

**3.24 Breast screening units should work with the NHSBSP to develop business cases for digital mammography. PCTs will need to give high priority to full implementation, with all units having at least one full-field digital mammography set by 2010.** All women under 50 routinely screened should have Direct Digital available for assessment visits by 2010.

**3.25** We also want to do more for women at high risk of breast cancer. There are women below the screening age who need regular surveillance because of a family history of breast cancer or other genetic conditions predisposing to cancer or previous radiotherapy exposure for treatment for Hodgkin's Disease which puts them at higher risk of developing breast cancer.

**3.26 Currently the surveillance of all women identified as being at high risk is managed at a local level to varying protocols. The NHSBSP offers the opportunity to manage such surveillance to national standards, ensuring women receive a consistent and high quality service. The NHSBSP will take on this surveillance, which**

**will include access to MRI scanning as stated in the NICE partial update of the Familial Breast Cancer Guideline (October 2006). It is expected that this new system will be in place from 2009.**

3.27 There is also a need to ensure that health inequalities are tackled with targeted programmes that increase the uptake of screening in poor communities and in BME communities. **Commissioners in PCTs with low coverage levels will wish to develop these programmes.**

### Improving bowel screening

3.28 Rollout of the NHS Bowel Cancer Screening Programme started in 2006. This programme is aimed initially at men and women aged 60-69, as this is the age group for whom the benefits of screening are expected to be largest. Test kits will be sent to participants every two years.

3.29 The programme is being coordinated through five regional hubs based on the five Connecting for Health clusters: Midlands & North West (located in Rugby), North East and Yorkshire (Gateshead), Eastern (Nottingham), Southern (Guildford) and London (Harrow). These hubs are responsible for the call and recall systems and for sending the test kits to people's homes. They also receive and process the completed test kits. People who are given positive test results are then booked in to local screening centres that are responsible for discussing the results with the patient and for undertaking colonoscopies.

3.30 Fifteen local screening centres were established in the first wave (2006-07) with a further 20 centres expected to come on stream in Wave 2. As at the end of October 2007, over 574,000 kits had been sent out and over 305,000 kits returned. Over 10,000 men and women aged 70 or over had self-referred for screening. Just under 5,500 men and women had positive test results and were referred to their local screening centre for further assessment. Over 3,500 colonoscopies had been undertaken, with over 1,600 polypectomies and

over 400 cancers detected. Full rollout to people aged 60-69 is expected by December 2009.

**3.31 As announced in September 2007, the NHS Bowel Cancer Screening Programme will be extended from 2010 to invite men and women aged 70 to 75 to take part.**

As a result, around one million more men and women will be screened each year. Research and pilot evidence shows this is feasible and effective and 61% of bowel cancers occur in those aged 70 and over.<sup>21</sup> Men and women aged 75 and over will be able to request a kit to be tested every two years.

3.32 This extension will be managed by NHS Cancer Screening Programmes in partnership with local health services. **In 2008/09, we will pilot the extension in five sites. This will enable us to learn lessons to inform the full rollout of the extension from 2010.**

**3.33 By the end of 2010, decisions will be taken about possible roll out to people in their 50s.** Depending on forthcoming research findings, a possible extension of the screening programme to people in their 50s could either be through the introduction of flexible sigmoidoscopy or by extending faecal occult blood testing (FOBT).

3.34 We will continue to monitor research evidence on other new technologies closely, such as immunological FOBT and CT colography and will take the opportunity presented by the national screening programme to pilot new approaches.

### Screening for other cancers

3.35 The cancer research community is committed to investigating screening approaches in other cancers, particularly in the most common forms of cancer where a national screening programme is most likely to be cost effective. Research is also underway into biomarkers of early cancers where patients often have no symptoms until the cancer has reached a very late stage, such as pancreatic cancer. We will continue to support and monitor this research and evaluate the potential for the introduction of new screening technologies as

the evidence develops, working closely with the UK National Screening Committee.

### **Screening for lung cancer**

**3.36** There is an increasing weight of evidence in support of introducing a trial for the screening of lung cancer. The Department of Health is leading work on behalf of the National Cancer Research Institute (NCRI) to commission research on the feasibility of a UK trial of CT screening for lung cancer. The National Institute for Health Research (NIHR) Health Technology Assessment programme has issued a commissioning brief, taking full account of the trials already underway in the US and Europe, with a view to funding feasibility studies as soon as possible. If there is progression to an exploratory trial and then a full randomised controlled trial, these will take a number of years to complete and will require consortium funding which will be brokered through NCRI.

### **Screening for prostate cancer**

**3.37** There is currently insufficient evidence to show that screening based on existing technology would reduce deaths from prostate cancer. The efficacy of the Prostate Specific Antigen (PSA) test for the screening or early diagnosis of prostate cancer remains controversial. Many cancers detected initially through the PSA test would have caused no problems during a man's natural life span. In addition, there is no consensus amongst clinicians on the best form of treatment for localised prostate cancer, be that surgery, radiotherapy or active monitoring. The Department of Health through its NIHR Health Technology Assessment programme is funding a trial of surgery versus radiotherapy versus active monitoring for PSA-detected localised prostate cancer at a cost of over £30m (the ProtecT trial). Associated research in partnership with Cancer Research UK is examining the impact of PSA testing. Results from major trials are expected in the next three to five years and the UK National Screening Committee keep prostate cancer screening closely under review.

**3.38** The Prostate Cancer Risk Management Programme (PCRMP) was introduced in 2002 to help GPs and practice nurses in advising men

without symptoms of prostate cancer on the implications of having a PSA test. This empowers men to make an informed choice on whether or not to have a test based on their own lifestyles and values. An evaluation of the PCRMP was funded by the Department of Health to help inform the future direction of the programme and the PCRMP pack is currently being reviewed. A consultation will be published in the spring, with the intention of launching the revised PCRMP packs in the summer of 2008. The review will take full account of the results of the Prostate Cancer in Ethnic Subgroups (PROCESS) study<sup>22</sup>, which showed that black men are three times more likely to develop prostate cancer compared to white men.

**3.39** The Department of Health is supporting the development of screening technology for prostate cancer by having a comprehensive research strategy into all aspects of prostate cancer. We are jointly with other National Cancer Research Institute (NCRI) members funding two NCRI Prostate Cancer Research Collaboratives and the Department of Health funded half of the original cost of £7.4 million. Following a review of progress by an international expert panel the Department of Health, Cancer Research UK and the Medical Research Council have agreed to provide a further three years funding of £3.9 million.

### **Screening for ovarian cancer**

**3.40** In ovarian cancer, the Medical Research Council, Cancer Research UK and the Department of Health are funding the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS), which began in 2000 and involves 200,000 post-menopausal women aged 50 to 74 across twelve UK centres. The trial is assessing the effectiveness of two possible methods of ovarian cancer screening, an annual CA125 test (a blood test for a cancer antigen) and an annual trans-vaginal ultrasound. Full results are not expected before 2012.

### **New developments in screening**

**3.41** Working with the UK National Screening Committee, we will continue to monitor and assess research evidence for the effectiveness of screening for these and other cancers such as

oral cancer and skin cancer, following the advice of the vision groups on these cancers. We will also monitor the emergence of potential new diagnostic markers as possible screening technologies of the future. High quality proposals for further research into biomarkers will be encouraged.

## Raising public awareness of cancer symptoms and encouraging people to seek help early

3.42 While enhancing the screening programmes will aid earlier diagnosis, this is only part of the action needed. We need to do more to raise public awareness of the signs and symptoms of early cancer and encourage people to seek help sooner.

3.43 Reviews and original research commissioned by the Department of Health and others have identified several factors which are associated with longer delay by patients in seeking help. These include:

- Failing to recognise that symptoms were serious or could be due to cancer;
- Social deprivation;
- Older age (especially for breast cancer);
- Atypical presentations; and
- Black and minority ethnic groups (for example, with mouth cancer).

3.44 **While some good work to raise cancer symptom awareness and encourage early presentation is already underway, we need to do more to provide coordinated support to local health services to deliver effective interventions. We will therefore establish a new National Awareness and Early Diagnosis Initiative. Led by the National Cancer Director, this initiative will bring together the NHS, representatives of Local Authorities, the Department of Health, the NCRI and the research community, cancer charities and patients to coordinate a programme of activity to support local**

**interventions to increase cancer symptom awareness and encourage earlier presentation. This activity will include:**

- **Developing measurement tools for symptom awareness;**
- **Developing and testing new interventions to raise awareness; and**
- **Supporting the rollout and evaluation of local pilots of validated interventions and disseminating information about best practice.**

## Measuring symptom awareness

3.45 Much of the existing information available on levels of cancer symptom awareness is piecemeal and tends to provide snapshots rather than an in-depth insight into nationwide levels of awareness and help-seeking behaviour.

3.46 We therefore need to establish the level of knowledge of cancer symptoms in the general population and track what interventions have an impact on this. **As discussed in chapter 2, Cancer Research UK is developing a modular assessment tool to assess levels of awareness of cancer risk factors and symptoms. This will enable change over time to be monitored and the impact of interventions to be evaluated.**

3.47 **Once the tool has been developed and validated, the Department of Health will use the tool to conduct regular national surveys of cancer symptom awareness.** PCTs and Cancer Networks can then use this information to benchmark their performance against the national picture.

3.48 **Given the evidence that late diagnosis is a particular problem in this country<sup>23</sup> and especially amongst deprived and BME groups, PCTs should give appropriate priority to local initiatives to promote early presentation by people with symptoms of possible cancer and will wish to monitor their progress in this area. To do this, they will be able to use the symptom awareness assessment tool at a local level to assess**

**changes in levels of symptom awareness and late presentation. Where they find evidence of low awareness and of late presentation, good PCTs and Local Authorities will take action to remedy this.**

### Programmes to raise symptom awareness and change behaviour

3.49 The research base on interventions which promote awareness of cancer symptoms and encourage behaviour change in relation to cancer is very small. Very few robust studies have been undertaken to assess the effectiveness of interventions.<sup>24</sup> An updated systematic review has recently been commissioned by Cancer Research UK.

3.50 However, there are several notable examples of awareness campaigns and pilot programmes to encourage help-seeking behaviour:

- The Open Up to Mouth Cancer campaign, run by Cancer Research UK and supported by the Department of Health, targeted at-risk groups with information about mouth cancer risk factors and symptoms;
- A pilot programme in Coventry funded by the Department of Health and signatories to the Prostate Cancer Charter for Action aimed to raise awareness of the prostate and its function, including among Afro-Caribbean men, using community health promotion techniques in pubs, clubs and workplaces;
- Psychosocial researchers have investigated the reasons for delayed presentation in women with symptomatic breast cancer and are conducting pilot work to develop an intervention to promote earlier presentation in women over 70 years<sup>25</sup>;
- The Breakthrough Breast Cancer 'TLC: Touch Look Check' campaign run with Marks and Spencer provided 50 million opportunities for women to receive a message on breast awareness during October 2007. A pilot programme in Camden funded by the Department of Health and Breakthrough Breast Cancer aims to increase awareness of breast cancer screening;
- The SunSmart campaign, discussed in chapter 2, also works to raise awareness not only of how to prevent skin cancer, but also how to notice the early symptoms; and
- The 'Don't Be a Cancer Chancer' symptom awareness campaign run by the Manchester Versus Cancer Alliance is using striking campaign messages in places such as supermarkets, pubs and bingo halls around Greater Manchester, encouraging people to go to their GP if they are worried about any possible symptoms.

3.51 It is also important that symptom awareness campaigns as far as possible adopt standardised messages based on the best available evidence. The Department of Health has worked with health professionals, patient groups and the voluntary sector to develop such standardised messages for prostate, bowel and lung cancer. **We will now work through the National Awareness and Early Diagnosis Initiative to develop equivalent messages for other cancers. We expect these messages to be developed over the course of 2008/09. These messages will be used in all relevant Department of Health funded information sources, including NHS Choices.**

3.52 Although the evidence to support different interventions is limited, there is a growing behavioural science literature which points to strategies that are effective in changing people's behaviour. There is also evidence to suggest that adopting a health related social marketing approach is improving people's health and reducing inequalities. Social marketing is the systematic application of marketing concepts and techniques to achieve specific behavioural goals relevant to a social good. It uses a range of commercial sector marketing techniques and puts a detailed knowledge of consumer behaviour at the heart of the development of behaviour change interventions, campaigns or programmes.

### Box 10: Spreading key messages on cancer within a community

Teams of local people in North East Lincolnshire are supported by clinicians and other professionals to use local knowledge to understand, target and engage communities in earlier presentation of cancer symptoms.

Early on, an 'Experts on the Ground' event brought people together to prioritise tumour sites and identify networks. Messages have been spread across buses and local media, in supermarkets, social clubs, pubs, community fetes, libraries, General Practice and across a range of community networks. The local fire service agreed to support messages targeting men using pictures of a fireman. Raising awareness is supported by deliberate links into local services. Men's health MOTs at a local drop in are being used to raise awareness of prostate cancer. The 'Don't Sit on It' campaign raises awareness of bowel cancer by targeting groups at bingos and community groups using bingo dabbers and beer mats.

Now half way through the programme, over forty local people are involved as volunteers. New resources have been produced and several hundred people reached across scores of community events. After being shown the fireman's publicity, local man John recognised symptoms and went to his GP. Early stage prostate cancer was diagnosed. He said, "A family friend showed me some of the posters and I immediately recognised symptoms I had been having. Without it things might have been a lot worse".

**3.53 The Department of Health is investing in a campaign that uses social marketing techniques to raise awareness of the signs and symptoms of breast, lung and bowel cancers and to encourage people who think they might have cancer to seek help earlier. The Improvement Foundation Healthy Communities Collaborative is working in 20 of the most deprived areas in the country to target those most at risk and is working with local people to develop and test methods of awareness raising. Full findings from the pilots will be available in 2009/10.**

**3.54 For pilot projects and campaigns such as these to be of maximum value, it is essential that they are properly evaluated and their findings disseminated. The National Awareness and Early Diagnosis Initiative, working with the NCRI, will therefore support high quality evaluations of pilot projects, promote the findings of these evaluations to encourage best practice and encourage more research in this field.**

**3.55 We will also pilot innovative approaches to raising awareness about the signs and symptoms of cancer, as well as prevention, by working with the Football Foundation, the UK's largest sports charity. The Football Foundation has already been successful in using the reach and appeal of football to engage with marginalised groups, helping deliver improved outcomes on a number of different social issues. We now believe it can help do the same for cancer and we intend to test and evaluate this approach. Details of this pilot will be announced in the New Year.**



### Box 11: Using health trainers to identify potential cancer symptoms

As part of the Improvement Foundation's Healthy Communities Collaborative, Health Trainers in Halton incorporated a new question into their interventions with individuals. The intention was to allow people to share any unexplained physical symptoms that might need further investigation. The Health Trainers operate from Halton's Healthy Living Programme which is a part of Halton and St. Helens PCT.

The new question they asked was:

*"Have you noticed any unusual physical changes which have not been explained or investigated by a healthcare professional?"*

Between the end of July and September 2007, 24 people were asked this question. Nine answered 'yes' to the question and were advised to follow this up with their GP or practice nurse. Tracking by the Health Trainers revealed that two people have no specific health problems requiring treatment, three people have a non-malignant disease and two were diagnosed with cancer. The results for the remaining two people were not recorded as they did not present themselves to their local surgery.

By including this simple question, advising presentation to a GP and following up the individuals, five people were found to have illnesses which might not otherwise have been diagnosed early. The impact of this therefore goes beyond cancer diagnoses and has the advantage of not having to mention the word cancer to the individual.

Halton and St. Helens PCT will now be using the question more widely, to see if it will pick up more patients who would not normally seek advice about their symptoms. This pathway enables non-clinical staff to support people around their physical concerns.

From January 2008 other lifestyle interventions in Halton will include the question about unusual symptoms. The question is now included in the exercise on prescription questionnaire, of people enrolling in smoking cessation groups, the healthy ageing questionnaire for over 50s, a new men's health project and is to be used by Health Trainers in St. Helens also.

This will increase the coverage across the patch to include 90,000 people in the most deprived groups.

## Working with primary care professionals to diagnose cancer earlier

**3.56** Primary care professionals have essential roles at all stages of the cancer care pathway. One of the most important is in the diagnosis of cancer.

**3.57** A GP with a list size of 1,800 patients can expect to see only eight or nine new patients with cancer each year and there many different types of cancer. The GP will also see hundreds of patients with signs or symptoms which could possibly be due to cancer, such as lumps, weight loss, bowel symptoms, coughs and breathlessness and difficulty swallowing.

Typically, a GP will see one new case each of breast, lung, prostate and colorectal cancer each year, one case of less common cancers such as ovary or pancreas every five or six years and some rarer cancers such as testicular cancer about once every 20 years. While the number of cancers detected through screening is increasing, the vast majority of cancer patients present first to a GP.

**3.58** In 2005, NICE published updated guidance for GPs and primary healthcare professionals for when a patient should be urgently referred to a specialist for investigation of suspected cancer.

### Box 12: Young people and cancer

In March 2007, Teenage Cancer Trust held its annual 'Find Your Sense of Tumour' conference for teenagers and young people with cancer, where they discussed their experiences of being diagnosed with cancer. Of the 360 teenagers and young people surveyed at the conference, 47% had visited their GP with symptoms four or more times before being referred to a specialist.

The survey question: How many times did you visit your GP with symptoms before you were referred to a specialist?

Answer: Once – 26%; two to three times – 27%; four to five times – 13%; and more than five times – 34%

3.59 However, several of the groups convened to inform the development of the Cancer Reform Strategy felt that more should be done to support primary care professionals in spotting potential cancer symptoms, accessing the appropriate diagnostic tests and making referrals to secondary care quickly when necessary. There is scope to go beyond checklists of the most significant symptoms to more sophisticated decision making tools which assess individual patients' risk of having, or getting, a specific cancer. **NCRI will be exploring what research is needed in this area.**

### Improving access to diagnostics

3.60 Improving access to diagnostics is the single most important priority in primary care to improve the early diagnosis of cancer. Greater access is needed both to diagnostic tests for initial investigations, mainly to exclude cancer and to specialist diagnostic services for patients with a high chance of having cancer. GPs, working to agreed protocols, need to be able to send patients for initial investigations such as MRI and CT scans, endoscopies and X-rays if they are concerned that cancer may be a possible diagnosis. This issue also forms an important component of the NHS Next Stage Review. Chapter 7 sets out some of the ways in which access to diagnostic services could be improved and diagnostic capacity increased.

### National audit in primary care of newly-diagnosed cancers

3.61 **Missed diagnosis of cancer has been identified as an important issue by the National Patient Safety Agency (NPSA). We now need to understand more about the nature and extent of delays in cancer diagnosis. Many GPs are already undertaking 'significant event reviews' regarding the diagnosis of cancer. We wish to build on this to establish a National Audit in primary care of all patients newly diagnosed with cancer. The audit will be undertaken in collaboration with the Royal College of General Practitioners (RCGP) and the NPSA.**

3.62 The RCGP and NPSA will be asked to consider and develop the best audit methodology. This audit will need to look at aspects such as:

- The number of visits to primary care with relevant symptoms before referral to hospital (delay pattern analysis);
- The interval from first attendance to referral or definitive diagnostic test; and
- Examining clinical practice against criteria for referral and prioritisation.

3.63 Findings from the national audit will then be used to make decisions about how best to provide more support to primary care professionals to ensure early diagnosis of cancer. We will discuss with the RCGP how lessons from the audit could inform the education and training of GPs, including through continuous professional development and appraisal. The audit could also assist in the development of decision aids to support healthcare professionals in assessing symptoms and making decisions about further investigation or referral.

### Working with other primary care professionals

3.64 Although GPs may play the key role in helping diagnose cancer, other primary care professionals can also play an important role. For example, the role that pharmacists have played in helping promote awareness of the signs and symptoms of lung cancer and in encouraging people with a persistent cough to visit their GP, provides an excellent example of the enhanced contribution that can be made. Social workers may also play an expanded role in helping identify potential cancer symptoms amongst at risk groups, such as older people or the disabled. **We will therefore involve professionals such as pharmacists and social workers as we develop the National Awareness and Early Diagnosis Initiative.**

## Chapter 4: Ensuring better treatment

### Chapter Summary

- More patients will benefit from the 14 day, 31 day and 62 day targets for cancer;
- Improving outcomes guidance will be fully implemented by 2010/11;
- The use of laparoscopic (keyhole) surgery for colorectal cancer will be enhanced through a national training programme and through patient choice;
- Major investments in staff and facilities will deliver world class radiotherapy services;
- The Department of Health will continue to work with NICE to ensure that all appropriate cancer treatments are appraised and that gaps between licensing and publication of guidance are minimised;
- Commissioners and providers should give high priority to safety issues related to radiotherapy and chemotherapy; and
- Further new developments in cancer treatment are anticipated over the next five years.

### Introduction

**4.1** Treatment for cancer has improved considerably over the past decade. In addition, around 1,500 multidisciplinary teams for cancer are improving the delivery of treatment and care for patients. We have seen a major increase in the use of effective new treatments approved by National Institute for Health and Clinical Excellence (NICE) and major reductions have been achieved in waiting times.

**4.2** To build on this progress and ensure better treatment for cancer we will:

- Go further on cancer waits to ensure patients no longer have to experience unnecessary delays for any treatment they may need;
- Ensure that reconfigurations are completed in line with improving outcomes guidance;
- Continue to improve the quality of cancer surgery and expand training in laparoscopic (keyhole) techniques and other surgical innovations;
- Encourage urgent expansion of local capacity in radiotherapy so that it can meet growing demand;
- Speed up the process of appraising new cancer drugs and monitor chemotherapy usage more closely;
- Encourage the speedy introduction of new innovations in cancer treatment into NHS practice; and
- Ensure better quality information is collected to drive up quality of treatment and improve outcomes for patients (see chapter 8).

4.3 This chapter sets out the actions which will be taken to ensure delivery of better treatment. Chapter 7 sets out how treatment and care can be delivered in the most appropriate settings.

### Going further on cancer waits

4.4 Excellent progress has been made on the current waiting time targets, with achievement at a national level as follows:

- two week standard (urgent GP referral to first hospital assessment): >99%;
- 31 day standard (from diagnosis/decision to treat to first treatment): >99%; and
- 62 day standard (from urgent GP referral to first treatment): >96%.

4.5 This progress has been achieved as a result of concerted effort and coordination across primary and secondary care. In 2006/07, over 630,000 people were seen under the two week standard, over 200,000 under the 31 day standard and over 80,000 under the 62 day standard, with less anxiety caused by waiting and greater chance of successful treatment if they are found to have cancer.

4.6 However, the current standards do not apply to all cancer patients. Only around one third of patients diagnosed with cancer come through the urgent GP referral route and thus fall under the two week and 62 day standards. Also, the 31 day standard only applies to the first treatments for cancer. It therefore does not cover second or third treatments when patients require several treatments in sequence, for example radiotherapy after surgery, nor does it apply to patients requiring treatment for recurrence of cancer.

4.7 The government made a commitment to "go further on cancer waits" in its 2005 election manifesto. Extensive consultation has been undertaken with key stakeholders to determine what the priorities should be in this area and how they should be achieved. The Cancer Services Collaborative has been undertaking pilots to test a range of new approaches to implementation.

**4.8 Following this work and based on advice from key stakeholders, we will now extend the range of patients who benefit from the current standards:**

- **The 31 day standard will be extended to cover all cancer treatments. Primary Care Trust (PCTs) and trusts will need to ensure that they are compliant with this extended standard for all patients receiving surgery and drug treatment by December 2008. The largest impact of this change will be in radiotherapy delivery, where increased capacity will particularly be needed and some areas will not be able to meet this deadline. PCTs should set out challenging goals for achieving this standard for radiotherapy, which should be approved by their SHA. We expect this standard to be fully implemented by December 2010;**
- **In addition to patients referred urgently by their GP, all patients with suspected cancer detected through national screening programmes will in future enter the 62 day pathway. Detailed guidance will be provided early in 2008;**
- **Hospital specialists will now have the right to ensure that patients who were not referred urgently by their GP, but who have symptoms or signs indicating a high suspicion of cancer, are managed on the 62 day pathway. In some parts of the country, this is already being done. As a matter of good clinical governance, such arrangements should be put in place in all localities during 2008; and**
- **As announced in September 2007, all patients referred to a specialist with breast symptoms, even if cancer is not suspected, should be seen within two weeks of referral. This is already being achieved in several centres and could be achieved elsewhere, for example by increasing capacity by training nurse practitioners to undertake clinical assessment. We expect this standard to be fully implemented by December 2009.**

4.9 Further guidance on delivering these cancer waits standards will be issued to the NHS in early 2008.

## Improving Outcomes Guidance implementation

4.10 Part of the purpose of the service reconfiguration recommended by the Improving Outcomes Guidance is to enable complex surgical procedures to be carried out by specialists. To see further improvements in cancer surgery it is essential that this reconfiguration is fully implemented nationally.

4.11 The timetable for implementation of the Improving Outcomes Guidance is as follows:

- Breast, lung and bowel – already implemented;
- Gynaecological, upper GI, urological and haematological – by the end of 2007;
- Head & neck and supportive & palliative care – by December 2008; and
- Children & young people's cancer, brain, sarcoma and skin – by 2010/11.

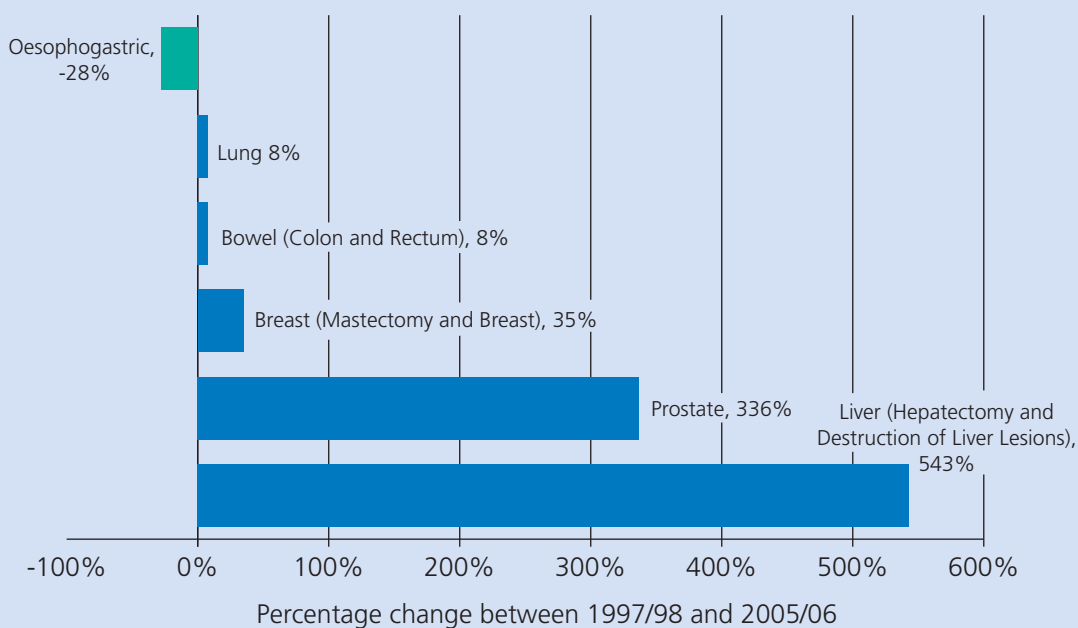
4.12 The Department of Health and the Healthcare Commission will continue to work together to ensure that implementation of this series of guidance is completed.

## Surgery

4.13 Surgery has been the mainstay of treatment for many types of cancer for many years. Surgery cures more patients of cancer than any other intervention. For most cancers, surgery is the principle treatment for the vast majority of patients. Exceptions to this include lung cancer, pancreatic cancer, haematological cancers and those cancers that present as disseminated disease without an obvious primary source.

4.14 For many cancers, surgery is used as the first treatment. In these cases, over 99% of patients requiring surgery are being treated within 31 days under the current standard. However, for some cancers such as bladder, pancreatic and skin cancer, it is relatively

Figure 7: Changes in surgical activity related to cancer



common for definitive surgery not to be the first procedure.

**4.15** Under the new extension to the 31 day standard NHS Trusts will need to ensure that patients undergoing definitive surgery as a second or subsequent treatment do not experience delays.

**4.16** Overall demand for cancer surgery is likely to rise based on current trends, although the pattern varies between cancer types. Figure 7 shows trends in activity related to different types of surgery, based on data from Hospital Episode Statistics.

**4.17** The quality of cancer surgery has improved and will continue to improve. More patients are being treated by specialist surgeons who gain expertise in particular procedures, such as oesophagectomy and prostatectomy and there is good evidence that this is leading to improved outcomes.

### Laparoscopic surgery for colorectal cancer

**4.18** Over the next five to ten years we can expect to see more widespread use of minimally invasive surgical techniques for cancer, including laparoscopic (keyhole) surgery and possibly robotic surgery for some cancers. The less invasive techniques should lead to lower morbidity and speedier recovery for patients as well as cost savings for the NHS due to reduced inpatient days, which could be reinvested to improve patient care further.

**4.19** Laparoscopic surgery for colorectal cancer has been approved by NICE, but is not widely available as only around five to ten percent of surgeons have been trained to use this technology. Patients cannot therefore always be offered this option and the benefit in terms of more rapid recovery that can go with it. Costs of standard and laparoscopic surgery are broadly similar.

**4.20** NICE made clear that laparoscopic colorectal surgery should only be performed by surgeons who had completed appropriate training in the technique and who performed the technique often enough to maintain competence. **To increase the use of this form of surgery, a pilot training programme for laparoscopic surgery will therefore be established which will be fully evaluated for potential national rollout.** Further information on this is in chapter 11.

**4.21** Positive NICE appraisals are usually covered by a three month funding direction which places an obligation on PCTs to fund the service recommended in order to make it “normally available” within three months. However, a waiver to the funding direction for laparoscopic surgery for colorectal cancer was issued by the Department of Health on 31 October 2006, to give the NHS sufficient time to build up the necessary expertise. **This waiver will be lifted in due course, so it will be important that the NHS prepares for the introduction of this technique locally. Trusts will need to:**

#### Box 13: Specialist surgery for oesophageal cancer

Oesophagectomies (an operation to remove the ‘food pipe’) and oesophagogastrrectomies (to remove both the food pipe and the stomach) are two examples of cancer surgery that are increasingly done by specialists.

In 1997/98, 309 surgeons in 147 Trusts carried out these operations. By 2004/05, they were concentrated in the hands of only 188 surgeons in 96 Trusts.

The impact of this has been significant – the number of patients that died in hospital following one of these operations almost halved in this period (from 9.4% to 4.9%).

Although there will be a number of factors that contributed to this, one is specialisation by surgeons and their teams.

- **Identify suitable surgeons (and their supporting teams) to receive national training and release them for this training;**
- **Allow some surgeons to become “laparoscopic colorectal surgery trainers” as part of the national programme;**
- **Put the necessary facilities and equipment in place to provide laparoscopic colorectal surgery; and**
- **Start to offer the option of laparoscopic colorectal surgery to patients as soon as they have the necessary capacity and expertise in place to do so and by December 2009 at the latest.**

## Radiotherapy

4.22 Radiotherapy has an important role in the treatment of many different forms of cancer. For some cancers radiotherapy may be the main form of treatment, such as for cancer of the larynx, where preserving the voice-box may be a high priority. For other cancers, radiotherapy may be used alongside surgery, for example in breast conserving procedures for breast cancer, or alongside chemotherapy such as for oesophageal cancer. Radiotherapy is also extensively used to alleviate symptoms of advanced cancer, such as pain from bone metastases. Experts estimate that at least half of all cancer patients require radiotherapy at some point in their care pathway.

4.23 The National Radiotherapy Advisory Group (NRAG) has submitted a report to Ministers entitled “Radiotherapy: developing a world class service for England”. Key findings from this report, which was published in May 2007, are as follows:

- The need for radiotherapy was underestimated in the past;
- Demand is set to grow over the next ten years;

- There is currently a 2.5 fold variation in radiotherapy activity between cancer networks, which cannot be attributed to differences in levels of need;
- On average around 30,000 fractions are currently being delivered per million population, with a range of 17,000 to 48,000 fractions per million between networks;
- By 2016 it is estimated that there will be a need for around 54,000 fractions per million population, requiring more staff and linear accelerator machines (linacs);
- The NHS needs to make best use of existing staff and equipment. Across a radiotherapy department an average output of 8000 fractions per linac (radiotherapy machine) per annum should be achievable immediately, working towards at least 8,700 fractions by 2016; and
- There is a clear need to collect better data on radiotherapy activity.

**4.24 To achieve a world class radiotherapy service local investment will be needed both in equipment and workforce.** Most (85%) radiotherapy is given as a second or third treatment after surgery and/or chemotherapy, or at the recurrence of cancer. **If NHS Trusts are to meet the new extension to the 31 day standard, increased capacity in radiotherapy will be urgently needed.**

### Radiotherapy facilities

4.25 Following the publication of the NHS Cancer Plan, over £500 million was invested in additional and replacement equipment for cancer, including 167 new linacs (October 2007 figures) for radiotherapy.

4.26 Despite this, the average number of linacs per million population is still below many European countries. A 2005 report from the ESTRO QUARTS project which compared the numbers of megavoltage therapy units (linacs and cobalt units) per million population for several European countries including England



showed that England has relatively low radiotherapy capacity.<sup>26</sup> This level of capacity not only limits patient care but also constrains research.

**4.27 Additional radiotherapy equipment will be needed in many parts of the country. Local decisions will need to be made regarding the siting of additional capacity, with patient convenience being taken into account. Where it is agreed to develop radiotherapy services on new sites these should be formally integrated into the existing network of radiotherapy provision.**

**4.28 PCTs working with each other in their cancer networks will want to review their local radiotherapy services to ensure that:**

- **Recommended levels of fractionation and linac productivity are achieved as set out in the NRAG report; and**
- **Providers have sufficient capacity to meet the widened 31 day waiting time standard for all radiotherapy within a specified timescale and by December 2010 at the latest.**

**4.29 In discussions held with commissioners there is recognition of the importance of ensuring that network plans for development of Radiotherapy services are compatible with each other before increased levels of radiotherapy capacity or new services are commissioned. SHAs should coordinate Network plans; where appropriate SHAs may wish to call on specialist commissioning groups to assume a coordination role.**

#### **Radiotherapy workforce**

**4.30** In spite of the increase in training commissions for therapeutic radiographers (rising from 135 in 1997 to 361 in 2005), this has been less effective than was anticipated due to a high attrition rate of 35%. A report commissioned for NRAG indicated that poor learning experiences in the clinical setting contributed to the high attrition rate and a

potential solution would be to provide a 'safe' learning environment for students in their first year of training. To facilitate this NRAG recommended the introduction of Virtual Environments for Radiotherapy Treatments (VERT) into radiotherapy training sites that simulate the radiotherapy equipment and treatment rooms. As part of the release of the NRAG report, five million pounds of capital funding was announced for VERT. This funding has now been allocated to higher education institutes and radiotherapy centres. **SHAs will wish to monitor the impact on attrition rates both at higher education institute and clinical placement radiotherapy centre level.**

**4.31 To achieve a world class radiotherapy service investment will be needed both in equipment and workforce. A long term workforce strategy should be developed to include an urgent review of workforce supply, demand and skills mix to identify the investment needed in both staff numbers and types of training commissions. SHAs will need to lead this work.**

#### **Proton therapy and other technological advances**

**4.32** Proton therapy is a very precise form of radiotherapy which can avoid damage to critical tissues near the tumour. Evidence is growing that proton therapy can be effective in treating a number of cancers. There is a proton therapy facility in the UK which has been running successfully for some years but it is limited by its design to treatment of eye cancers. From April 2008, proton therapy for suitable cancers other than eye cancers will be nationally commissioned from overseas by the National Commissioning Group. The Department of Health will now consider options for providing modern proton therapy services in this country

**4.33** The Department of Health will also continue to work closely with relevant experts to monitor other new developments in radiotherapy, such as intraoperative radiotherapy for breast cancer.

## Drug treatments

4.34 Drug treatments for cancer have developed substantially over the past 20 years and are set to develop further. Research within the UK and elsewhere has led to the development of:

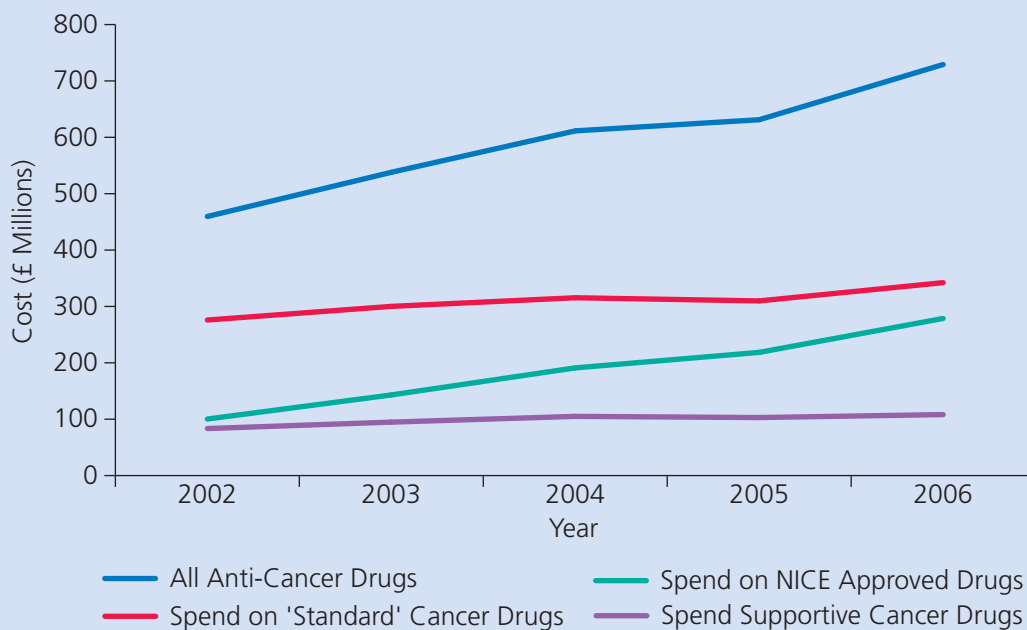
- Combinations of drugs that have been shown to be active against cancers which were previously considered resistant to drug treatment;
- A new generation of hormonal therapies introduced in the treatment of breast and prostate cancer; and
- A new generation of anticancer treatments targeted against specific molecular abnormalities present in some forms of cancer. Examples include imatinib (for chronic myeloid leukaemia), rituximab (for some types of lymphoma) and trastuzumab (herceptin, for some breast cancers).

4.35 The number of new drugs licensed for use in different cancers is likely to grow considerably over the next decade. Information provided by industry sources indicates that more than half of all new drugs currently in the industry pipeline are being developed to target cancer.

4.36 It is important that all patients have access to clinically appropriate and cost effective treatments and the establishment of the National Institute for Health and Clinical Excellence (NICE) plays an important part in making this happen. NICE is an independent body and if it recommends that a treatment should be used in the NHS then a PCT must fund its use for eligible patients (defined as those who meet the criteria specified in the NICE guidance) within three months of NICE's final guidance being issued. This ensures that there is national consistency in how the NHS uses new treatments.

4.37 Over the past seven years, NICE has undertaken 44 appraisals of cancer drugs, representing about a third (34%) of all its

**Figure 8: Expenditure on cancer drugs dispensed in hospitals and in the community from 2002 to 2006<sup>27</sup>**



technology appraisals. Thirty nine of these appraisals have partly or fully recommended the use of the treatment in the NHS. The 44 appraisals relate to 23 different cancer drugs, some of which have been appraised for more than one indication (use).

**4.38** In line with this, expenditure on anticancer drugs has increased as indicated by Figure 8 (on previous page).

**4.39** In total, approximately £729m was spent in 2006 on drug treatment for cancer. The fastest growth relates to the more newly licensed anticancer drugs which have been approved by NICE. Over an 18 month period between 2003 and 2005, the median rate of usage for 14 anticancer drugs approved by NICE increased by 47 percent.

**4.40** However, despite this several problems with access to drug treatments for cancer have been identified on which action is needed:

- Local decisions where NICE guidance is not available;
- Time lags before NICE makes its appraisal decision;
- Variable use of NICE-approved drugs across the country;
- Poor local planning for chemotherapy services in some areas; and
- Ensuring patient safety.

**4.41** One of the issues that has been raised by some stakeholders leading up to this strategy is the issue of pricing of cancer drugs. The wider issue of pricing of drugs is being dealt with separately by the Department of Health and is therefore not addressed in this document.

### Local decisions where NICE guidance is not available

**4.42** There remain concerns about the process prior to drugs being referred to NICE and also during the period where NICE is considering drugs. We have listened to these concerns as

this strategy has been developed and agree they need to be addressed.

**4.43** When NICE guidance is not yet available, it is for PCTs to determine whether or not to fund a drug locally should they receive a request from a doctor/patient for its use. They have to base their decision on an assessment of the available evidence, the circumstances of the patient requiring the treatment and the health needs of their local population. It is not acceptable for a PCT to use a lack of NICE guidance as a reason to reject an application for a drug. This was emphasised by the Department in December 2006 in the document *'Good Practice Guidance on Managing the introduction of New Healthcare Interventions and Links to NICE Technology Appraisal Guidance'* which updated and clarified the messages contained in Health Service Circular 1999/176.

**4.44** The updated advice also notes that there are a number of valuable sources of information available to the NHS, which can help in making decisions about the use of new treatments where NICE guidance is not available. Most of these sources are available online and include summaries of the available evidence on the safety and effectiveness of new treatments. The good practice guidance makes clear that these sources can help local NHS organisations make more informed decisions. PCTs could choose to work together on these decisions, for example across an SHA area. Information sources of particular relevance to cancer drugs are:

- London Cancer New Drugs Group which develops recommendations for the managed entry of new treatments in cancer across London. Its recommendations can be found on the National Electronic Library for Medicines website (see [www.druginfozone.nhs.uk](http://www.druginfozone.nhs.uk));
- National Prescribing Centre (NPC) New Medicines Scheme which provides a range of evaluated information, both pre-and post-market launch, on new medicines (see [www.npc.nhs.uk](http://www.npc.nhs.uk)); and

- Scottish Medicines Consortium (SMC) which provides advice to NHS Boards and their Area Drug and Therapeutics Committees (ADTCs) across Scotland about the status of all newly licensed medicines, all new formulations of existing medicines and new indications for established products (licensed from January 2002). While the guidance is aimed at NHS Scotland, the analysis of the evidence considered by the SMC is a useful source of information to all local NHS managers when making decisions on the introduction of new medicines (see [www.scottishmedicines.org.uk](http://www.scottishmedicines.org.uk)).

**4.45 It would be good practice for all PCTs considering applications for new cancer drugs to consider the information available from these sources as a minimum as part of their decision-making process.**

## NICE appraisals

4.46 Whilst it is right that decisions lie with PCTs when NICE guidance is not available, it is clear that we should reduce the period when local decisions are necessary to a minimum by ensuring that NICE issues guidance as close as possible to the date when a drug is licensed. We will achieve this by ensuring that the NICE fast track (Single Technology Appraisal) process, launched in November 2005, is used appropriately and works as effectively as possible. We have already seen how successful this process can be; development of guidance on the use of Herceptin for early breast cancer started in parallel to the licensing process and NICE was able to issue its draft recommendations within two weeks of the drug being licensed for this use. We need now to ensure that the process can be as efficient for all suitable drugs. **The Department of Health will continue to work with NICE to ensure that all appropriate cancer treatments are considered by the Single Technology Appraisal process and that this process works as effectively as possible.**

4.47 We have also heard from a number of stakeholders that they would welcome a guarantee that NICE will by default appraise significant new cancer drugs and license

extensions. This would provide greater certainty at an earlier stage on whether NICE guidance will be forthcoming on individual drugs. **We therefore propose that as a default position all new cancer drugs and significant new licensed indications will be referred to NICE, providing that NICE agrees that there is a sufficient patient population and evidence base on which to carry out an appraisal and that there is not a more appropriate alternative mechanism for appraisal.**

4.48 There is also more general (non-cancer specific) work being undertaken by NICE to review its technology appraisal methodology. This work will involve a public consultation.

4.49 We should remember, however, that the NHS does not have a limitless pot of money. It is therefore important that we use treatments that are sufficiently effective to justify their cost. We therefore need to accept that there will be occasions when NICE, having considered all the evidence and views from stakeholders, will not recommend that a particular treatment is a suitable use of NHS funds. Such decisions can, understandably, be hard for patients, their families and sometimes their clinicians to understand and accept.

4.50 If NICE does not recommend a treatment this does not mean that a clinician cannot discuss it with their patient. It is good practice for a clinician to discuss all clinically appropriate treatment options with their patients. However, it will be important if a treatment that is not available on the NHS is discussed, that a patient understands why it is not available on the NHS.

## Reducing variation in drug usage

4.51 Concern has also been expressed regarding variations in usage of anticancer drugs between different cancer networks in England once approved by NICE. A report issued by the National Cancer Director in September 2006 showed that the use of drugs increased across the country following a positive appraisal from NICE – an increase of 47% from late 2003. It also showed that variation in the use of these drugs reduced across the country. Although there is still scope to reduce this variation in

usage further, the report clearly showed that the NICE process is working ensuring increased access to drugs and less variation in their use, but we need to keep on top of this. **The National Cancer Director will therefore repeat his evaluation of NICE-approved cancer drug usage during 2008 to ensure that patients across the country continue to have access to cancer drugs positively appraised by NICE.**

4.52 Current audits do not collect sufficient information to understand why these variations occur. **We will therefore ask all chemotherapy service providers to collect and return an agreed dataset on all patients receiving chemotherapy.** Further information on data collection is provided in chapter 8.

4.53 Trusts providing chemotherapy are already required to collect the outpatient commissioning data set and reference costs to support the introduction of Healthcare Resource Group 4 (HRG4, the latest national currency system, is already being used for costing purposes). However, chemotherapy cost data submitted in June 2007 as part of the 2006/07 reference cost collection were not robust. **The introduction of HRG4 for chemotherapy payment will be greatly facilitated by e-prescribing and trusts that have not already done so would be wise to invest in these. PCTs should incentivise this through commissioning contracts and monitoring.**

### Supporting better local planning for chemotherapy

4.54 Better data collection on chemotherapy activity will also aid PCTs in their planning. As expenditure on cancer drugs continues to increase, financial and capacity planning is essential both before and after NICE appraisals.

4.55 PCTs, working through cancer networks, are responsible for planning the introduction of new treatments for cancer. The Chemotherapy Planning Oncology Resource Tool (C-Port) has recently been developed through a partnership with industry, the Cancer Action Team and the NHS to support local planning. **PCTs will expect providers to demonstrate that they have**

**planned for the safe introduction of new drugs in a thorough and cost-effective way. Use of the C-Port tool will enable Trusts to do this.**

### International comparisons of drug utilisation

4.56 Usage of new anticancer drugs is estimated to be considerably lower in England than in other developed countries, with usage at approximately 60 per cent of that in other major European countries. An analysis by the Association of the British Pharmaceutical Industry (ABPI) indicates that the usage of anticancer drugs across Europe will continue to increase. The actions set out above will increase the use of anticancer drugs in this country. **As this strategy is implemented, we will work with our partners in the pharmaceutical and biotechnology industries to continue to monitor how use of anticancer medicines in the NHS in England compares to other European countries.**

### The National Chemotherapy Advisory Group

4.57 The Department of Health has established a National Chemotherapy Advisory Group (NCAG) which is considering all aspects of chemotherapy using a care pathway approach (assessment; decision making; prescribing; dispensing; delivery; reassessment and management of complications). The NCAG report which is due in spring 2008 will recommend next steps for chemotherapy services in general. In particular it will highlight:

- The year on year increases in chemotherapy activity;
- Potential new service models;
- Out of hours management and the importance of information about an individual's care being available across a network, especially as patients may present as an emergency at a location separate from that in which their treatment was delivered;
- Governance structures;

- Specific safety issues, especially those related to oral chemotherapy;
- The management of febrile neutropenia;
- Workforce requirements; and
- Guidance for commissioners.

## Ensuring safe delivery of chemotherapy

**4.58** The cancer peer review programme has shown that there are significant weaknesses in the way that cancer services are delivered. These include:

- Poor governance and safety arrangements both within and between organisations;
- Poor and cramped environments;
- Overstretched services; and
- Some small, poorly set up services with minimum infrastructure.

**4.59** These weaknesses in chemotherapy systems are also reflected in reports to the National Patient Safety Agency (NPSA). Along with missed diagnosis of cancer (see chapter 3) and radiotherapy errors, chemotherapy errors are one of the three areas of concern related to cancer highlighted by the NPSA.

**4.60** PCTs working with each other in their cancer networks will want to undertake a review of the safety of their chemotherapy services. They should set out in clear specifications which treatments should be provided in what locations and to what safety specifications, taking account of forthcoming advice from the National Chemotherapy Advisory Group.

## Auditing cancer treatments

**4.61** Building on the existing national clinical audits for several cancers, we need to collect, analyse and feedback more information about treatment and outcomes for cancer patients. National comparative audits will help clinical teams and commissioners to monitor and improve service quality. The field of cardiac

surgery has pioneered the publication of risk adjusted clinical outcomes for hospitals to help patients with their decisions when undergoing elective surgery. Similar information could and should be made available for cancer patients. Chapter 8 sets out in detail how we will collect more information on cancer services and outcomes.

## New developments in cancer treatment

**4.62** The pace of change in cancer treatment is fast and it is likely that improved forms of surgery, radiotherapy and drug treatment will continue to be developed. Other approaches, such as photodynamic therapy, may also have an increasing role in the treatment of cancer. Provided that these new treatments are clinically and cost effective, we will want to ensure that they are rapidly made available to all patients who could benefit.

**4.63** The National Cancer Research Network (NCRN) has an important role to play in identifying potential new therapies and ensuring that clinical trials are undertaken in a timely manner. In doing this, NCRN engages with both pharmaceutical companies and NICE with the aim of maximising the impact of NCRN trials on subsequent NHS practice.

**4.64** In October 2007, Lord Darzi announced the creation of a new Health Innovation Council. It will give a lead on innovation from discovery to adoption. The Council will advise on how best to overcome barriers to the use of cost-effective new medicines, medical technologies, procedures and processes throughout the NHS and social care system. It will encourage a greater focus on innovation by supporting the discovery and development of new products and techniques and encouraging greater adoption of models of care where there is good evidence of improved outcomes. Its work will be closely linked to the work of commissioners, especially in light of the world class commissioning programme which seeks to improve health outcomes by involving the public, their wider partners and clinicians in the design of services that are innovative and evidence based.

4.65 The groups who met to discuss their 2012 visions for particular cancers and groups of cancers made predictions about how cancer treatment will change. Some of these are set out below.

#### Box 14: Breast cancer

- More new drugs available for early and advanced disease; and
- More surgeons will have been trained in oncoplastic techniques.

#### Box 15: Colorectal cancer

- Surgery will remain the mainstay of treatment for most patients, but laparoscopic surgery will be becoming the norm at least for elective surgery for colon cancer in combination with Enhanced Recovery Programmes;
- Novel techniques (such as transanal excisional microsurgery – TEMS) will be available in major centres for highly selected groups of patients;
- Increase in preoperative radiotherapy and Image-Guided Radiotherapy; and
- Chemotherapeutic agents will be more widely used in the adjuvant setting.

#### Box 16: Lung cancer

- Treatment will be more complex (such as parenchymal – sparing surgery, combination chemo-radiotherapy, biological therapies etc); and
- New, less toxic, drugs are likely to be available and methods are likely to become available to better individualise therapy.

#### Box 17: Urological cancers

##### *Prostate*

- The ProtecT trial will have reported its early findings, informing a clinical consensus on the most appropriate treatment options for localised prostate cancer;
- The use of laparoscopic and robotic surgery, brachytherapy and active surveillance will continue to increase;
- More evidence will be available on newer treatments, such as HIFU and Cryotherapy; and
- For more advanced disease, there will be more chemotherapy, more radiotherapy, new hormonal treatments and novel approaches.

##### *Other urological*

- Increased use of laparoscopic surgery, as well as techniques such as radiofrequency ablation, cryotherapy and high intensity ultrasound; and
- More targeted therapies and more evidence to support concurrent chemotherapy and radiotherapy.

**Box 18: Haematological cancers**

- More targeted therapies and an associated increase in intravenous chemotherapy; and
- Expansion in use of autologous and allogeneic transplantation in nearly all haematological malignancies and cellular therapy for certain malignancies.

**Box 19: Gynaecological cancers***Vulval*

- Use of sentinel lymph node assessment is likely to become established in clinical practice; and
- Reconstructive surgery may have an emerging role.

*Endometrial*

- Greater use of laparoscopic surgery;
- More cytotoxic chemotherapy will be used in both adjuvant and advanced disease; and
- The role of chemotherapy with radiotherapy in place of radiotherapy alone may be established.

*Cervical*

- Mainstay for advanced disease will remain chemotherapy with concomitant radiotherapy; and
- Greater laparoscopic surgery expected for early stage cervical cancer management.

*Ovarian*

- Greater reliance on neoadjuvant chemotherapy;
- More interval debulking surgery and radical cytoreductive surgery, as well as more surgery for selected cases of recurrent cancer and palliative surgery; and
- More established role for intraperitoneal chemotherapy.

**Box 20: Upper gastrointestinal cancers**

- More targeted therapies and neoadjuvant chemotherapy; and
- More need for radiotherapy.

**Box 21: Head and neck cancers**

- More targeted therapies, which will require more sophisticated molecular and immunohistochemical profiling of cancer specimens; and
- More complex advanced radiation techniques.



**Box 22: Thyroid cancer**

- Increased use of radioactive iodine and other targeted radioactive substances; and
- More node dissection as part of surgery.

**Box 23: Brain and Central Nervous System cancers**

- More combination therapy including surgery with chemo-radiation;
- More highly conformal and hyperfractionated radiotherapy; and
- Proton therapy, especially for children.

**Box 24: Sarcoma**

- Increased use of conformal radiotherapy and proton therapy;
- More preoperative radiotherapy; and
- New drugs.

**Box 25: Skin cancer**

- More targeted adjuvant chemotherapy and topical treatments;
- Increased use of photodynamic therapy and Mohs' micrographic surgery; and
- Possible new drug agents for patients with advanced disease.

## Chapter 5: Living with and beyond cancer

### Chapter Summary

- Commissioners should ensure that NICE guidance on supportive and palliative care is implemented as planned by December 2008;
- National information pathways and tailored information prescriptions will help to ensure that patients receive high quality information at each step in the care pathway;
- All senior cancer professionals will, over time, be expected to demonstrate that they have the necessary competencies in face-to-face communication;
- Improved information and communication will empower patients who wish to be involved in decision making;
- Commissioners and providers should ensure that the critical roles of clinical nurse specialists in information delivery, communication and coordination of care are supported;
- A new national cancer survivorship initiative will be established; and
- Progress on improving the experience of cancer patients will be monitored through annual surveys.

### Introduction

**5.1** The NHS Cancer Plan highlighted the fact that the diagnosis and treatment of cancer can have a devastating impact on the quality of patients' lives and that of their families and carers. Cancer patients face uncertainty and may have to undergo unpleasant and sometimes debilitating treatments. Patients and their families and carers, need access to information and support throughout the care pathway.

**5.2** Many patients find the following times particularly challenging: the time around diagnosis; the period immediately following completion of treatment; the time of any relapse and the time when it is clear that the end of life is approaching.

**5.3** The incidence of cancer is rising, due mainly to the ageing population. Survival rates for

cancer are also improving, with ten year survival rates having doubled in the last 30 years and continuing to increase. This means that the total number of people living longer with cancer is growing considerably. Many patients who are cured of their cancer may be left with physical or psychological effects from the diagnosis and treatment of their disease. Some cancer patients will live for many years receiving active treatment as their disease relapses and remits. As more patients become long term survivors of cancer it is increasingly important that they should be provided with the assistance they need to resume as normal a life as they can.

**5.4** National Institute for Health and Clinical Excellence (NICE) issued guidance in 2004 on the provision of supportive and palliative care for adults with cancer. In response to this, cancer networks have developed action plans

for implementation of this guidance. However, the extent of implementation to date has been mixed and the target of full implementation by December 2007 will not be met by all cancer networks. In recognition of some of the difficulties faced by networks, **we have extended the deadline for implementation to December 2008. We remain absolutely committed to the full implementation of the guidance. Chapter 9 sets out how good commissioners should use the tools at their disposal to ensure this happens. The Cancer Action Team will continue to have an important role to play in developing and spreading good practice in this respect.**

5.5 However, our determination to improve the experience of people living with and beyond cancer does not begin and end with achieving full implementation of the NICE guidance. We want to empower patients to:

- Fully understand about their cancer and its management;
- Be involved in decision making as they wish; and
- Make choices about their care as they see fit.

5.6 This chapter sets out a range of initiatives to improve patients' experience of living with and surviving cancer. In particular, it focuses on:

- Information, communication, decision making and choice;
- Coordination and continuity of care;
- Psychological support;
- Supportive and palliative care;
- The critical importance of Clinical Nurse Specialists (CNSs);
- Appropriate training for healthcare professionals;
- Helping patients meet the cost of cancer;

- Surviving cancer; and
- Measuring patients' experiences as a mechanism for improving the quality of services.

### Information, communication, decision making and choice

5.7 Patients, health professionals and cancer charities who were consulted during the development of this strategy strongly recommended that the issues of information, better face-to-face communication and support for decision making should be given the highest priority with regard to actions to improve patient experience. Integrated action on these areas should now be taken at both national and local levels.

### Information and communication

5.8 Access to high quality information is a prerequisite for patients to be able to participate in decision making about their care and to reduce their fear of cancer. Providing information, alongside the support to understand and act on that information, can empower patients to retain or regain control over lives.

5.9 Individual patients will want to acquire information in different ways. For many, face-to-face communication with a health professional they trust is of paramount importance. Many will also wish to supplement face-to-face communication with other types of information. Some will want to discuss their condition with others who have experienced similar challenges.

### Face-to-face communication

5.10 Evidence has shown that the communication skills of health professionals can be improved by training. Good communication skills underpin all elements of care and will enable staff to encourage patients to discuss their needs and preferences.

5.11 A national programme for advanced communication skills training for senior healthcare professionals has been developed for cancer. Since 2003, 150 facilitators have been trained to deliver three day courses for senior

### Box 26: Our vision for informing, engaging and empowering patients

- Face-to-face communication with healthcare professionals should enable those affected by cancer to gain a clear understanding of their condition, have their concerns and preferences elicited and become engaged in decisions about their care;
- People affected by cancer should be offered high quality information at key points in their cancer journey, tailored to their individual needs. Some patients will need additional support to understand and act upon the information they are given;
- Information delivery should be an integral part of each step in the care pathway. It should reinforce face-to-face communication with a health professional. It should be available in primary and secondary care and from other outlets including dedicated information and support centres and libraries;
- Information needs to be evidence based, balanced, regularly updated and composed in plain language. It needs to be culturally sensitive and available in a variety of formats. It should include personalised details, be locally customised and be available with a focus suitable to the patient's needs at a given point in time; and
- The purpose of communication and information is to inform and empower patients so that they can play an active role in decisions about their care and treatment if they so wish.

health professionals. 1,300 health professionals have participated in these courses.

**5.12 The current three variants of the course for advanced care professionals are being merged into a single course to facilitate national rollout. The course now needs to become standard local practice. The expectation is that over time all senior healthcare professionals will be able to demonstrate that they have the level of competencies to communicate complex information, involve patients in clinical decisions and offer choice, as part of their professional development and basic competence. Primary Care Trusts (PCTs) should ensure that they commission services from healthcare professionals who have received training and can demonstrate this through, for example, peer review.**

**5.13 Furthermore, in addition to training senior healthcare professionals, we need to ensure general and community based clinicians and other healthcare staff who treat and support cancer patients have had access to good communication skills training at a range of levels. Continuing Professional Development needs to be in place for this.**

**5.14 Specific communication skills are needed for effective face-to-face communication with children and young people. A number of successful pilots have been run with healthcare professionals working in this area and a course, based on the national model, will be developed.**

#### **Information products, pathways and prescriptions**

5.15 There are a number of high quality information products for cancer patients, frequently produced by cancer charities. These cover a wide range of topic areas, such as cancer and its treatment, local services, returning to work and financial benefits and are available in different formats (electronic, printed, audio, video etc.).

5.16 Cancer networks have been working with the Cancer Services Collaborative Improvement Partnership to develop standardised information pathways, establishing the different types of information product that patients with specific cancers may wish to access at different key points in the care pathway. Over 160 pathways have been mapped and twenty one cancer networks have at least two tumour specific patient pathways agreed. Work to collate these locally produced patient information pathways

into national pathways is complete for ten different cancer types.

5.17 However, there are several ways in which information for cancer patients needs to improve. In particular:

- There are gaps in the information provided for some of the less common cancers and in relation to survivorship, relapse and advanced cancer;
- About 50% of information is locally produced, without necessarily having the benefit of expert input and quality assurance;
- There is no current capacity to tailor information significantly for individual patients;
- We do not have a repository of bite sized pieces of information focusing on particular aspects of care;
- While some cancer networks have information managers in post, others do not; and
- There is currently no dedicated training available for Multidisciplinary Team (MDT) members on patient information delivery.

5.18 The Cancer Reform Strategy therefore outlines a range of initiatives to improve patient information products and pathways.

**5.19 Our immediate next step is for cancer networks to adopt and implement the tumour specific national information pathways which will be launched in 2008. This will make nationally agreed information available to frontline cancer health professionals to offer to patients at key points in their cancer journey.**

5.20 *As set out in the White Paper **Our health, our care, our say: a new direction for community services**<sup>28</sup> we are also introducing 'information prescriptions'. These personalised prescriptions will draw on local as well as national knowledge and information and*

will guide people to the relevant websites, telephone numbers and support groups for their condition, as well as providing information directly to patients at appropriate times during their care pathway.

5.21 We are piloting information prescriptions in twenty sites during 2007, including in four sites focusing on cancer (County Durham, Mid-Trent, Queen Elizabeth Hospital Birmingham and Royal Marsden Hospital London). These pilots are being run in partnership with voluntary organisations such as Cancerbackup and Macmillan Cancer Support, testing prescriptions based on network standardised prescription pathways. The evaluation of the pilot programme, which will take place during 2008, will inform the national implementation of information prescriptions for all people with long-term conditions, including cancer. Information on the initial findings from the early part of the piloting programme is now available on-line at [www.informationprescription.info](http://www.informationprescription.info). A specific post has been funded by the Cancer Action Team to work alongside the cancer pilot sites and share their learning with the other<sup>26</sup> cancer networks.

**5.22 To support the introduction of information prescriptions, a three-way partnership between Cancerbackup, Cancer Research UK and Macmillan Cancer Support is developing a system to enable health professionals to generate tailored information prescriptions at any point in the cancer pathway. The system will draw on high-quality national content to make up the information prescription, whilst also ensuring the local cancer network information leads and MDT teams are able to add local details. The project will be developed in 2008 for roll out in 2009.** The system is intended to be of use for any health or social care professional engaged in cancer care.

**5.23 Infrastructure and support is also needed at a network level to achieve improvements in patient information delivery. Cancer networks without a patient information manager are encouraged to**

**consider creating this post and to identify patient information leads in each trust in the network.**

5.24 Providers will wish to consider how they can best audit information delivered to individual patients and whether this is meeting patients' needs. Particular attention should be paid to the needs of at risk groups.

### Decision-making and choice

5.25 Patients with cancer vary in the extent to which they wish to be involved in decision-making. Some wish to take an active role, others wish to share decision-making with the health professionals caring for them and others wish to adopt a passive role. Patients should be free to adopt any one of these roles, or indeed to be active about some aspects of their care and passive about others. One of the responsibilities of a clinician caring for a patient is to discover from the patient what role or roles they want to adopt and to ensure that, irrespective of their decision, they are treated with dignity and respect.

5.26 Some patients will wish to make choices about the team or hospital they want to deliver care at different points in the care pathway.

They should be able to do so, choosing from providers that are compliant with relevant Improving Outcomes Guidance. In order to make choices that are appropriate to their own circumstances patients will need good information on the availability of services and on outcomes. Chapter 8 sets out how we will collect and publish data on services and outcomes through the establishment of a major new cancer intelligence initiative.

5.27 Experience outside cancer and from international settings has shown that the introduction of the offer of choice can result in improvements in service quality and timeliness. Services which are below average may be incentivised to put things right, so as not to lose patients to other providers.

5.28 It is important to recognise that choice is not simply about the location of care. Patients told us that they expect to be told of all clinically appropriate treatments, even if those treatments were not funded by the NHS (see chapter 4). Examples of the types of choices that patients might have in the future are set out below.

5.29 One important use of information is to help patients make informed treatment choices.

#### Box 27: Choice

##### Choice of Treatment

A woman with a large cancer in her left breast would be recommended to undergo a mastectomy (removal of the breast). Some hospitals can offer immediate breast reconstruction but in others the patient will need a separate operation at a later date. A patient may wish to choose the team that offers the same day operation.

##### Choice of Treatment

A man with bowel cancer needs surgery to remove the tumour. His surgeon can perform a standard operation to remove it requiring a major incision and hospital stay of around 10-14 days. A team in a neighbouring hospital have recently been trained to remove such tumours using a new keyhole surgical technique offering a faster recovery time. He may wish to choose the new treatment, even if it means travelling further.

##### Choice of Location

A patient living in Exeter is diagnosed with throat cancer and needs radiotherapy requiring 30 daily attendances at hospital over 6 weeks. He would prefer to have this treatment in Derby, where his daughter lives and would like to be able to choose to have the treatment there instead.

**Box 28: Informed decision making**

Shared decision-making about treatment options is important, but not widely practised in clinical care. Patient decision aids have been shown to increase patients' knowledge, involvement in decision-making and preventative behaviour and they lead to more appropriate use of tests and treatment. In some circumstances they have also been shown to improve cost effectiveness by reducing the use of unnecessary or unwanted interventions (Picker Institute).

The Urology Informed Decision Making project has been piloting the implementation of decision aids for early stage prostate cancer into routine practice in the NHS since 2004. Phase I was piloted using US materials in four hospitals and the findings have been fed into Phase II which is being piloted in six further sites. This phase of the project is developing patient booklets and DVDs suitable for UK practice, along with delivering staff training workshops and staff training DVDs. The project is due to rollout the materials from April 2008 using established cancer networks.

Some good practice models exist of how people with cancer can be involved in these choices through the use of decision aids. One such example is below.

**Coordination and continuity of care**

**5.30** Care for cancer patients is complex and often involves multiple different health professionals working in the community, in secondary care and in specialist centres (see the box below for one example). Good coordination of care is therefore imperative.

This requires effective systems to be in place, so that care is seamless from a patient's perspective.

**5.31** The establishment of multidisciplinary team working has been critical to improvements in coordination of care for cancer patients over the past few years. Within these teams, MDT coordinators and clinical nurse specialists have often taken the lead in ensuring continuity, coordination and smooth transitions between hospital and community.

**Box 29: Health professionals involved in Jim's cancer journey**

Good coordination is vital given the variety of health professionals who can be involved in a patient's care. Jim, a patient with bowel cancer, kept a record of all the people who were involved in treating and supporting him over a 26 month period.

In the hospital there were 111 staff:

- **22 doctors** (including consultant surgeons, anaesthetists, haematologists, oncologists, radiologists, pathologists and junior doctors);
- **63 sisters/nurses** (including clinical nurse specialists, nurses in theatre and on wards, nurses specialising in areas such as endoscopy, stoma care and pain management and healthcare assistants);
- **10 allied professionals** (including a physiotherapist, dietician and radiographers who take scans); and
- **16 other healthcare staff** (such as pharmacists and laboratory technicians).

In the community there were 15 staff:

- **3 GPs; and**
- **12 district and practice nurses** (including out of hours support).

**5.32 Commissioners will want to work with providers to ensure they have robust systems in place to ensure that patients experience good continuity of care.**

These include:

- Full assessment of an individual patient's needs at key stages in the care pathway and the development of formal care plans such as for diagnosis; end of treatment; relapse; and as end of life approaches;
- Care plans should be communicated to all teams / professionals involved in the patient's care in a timely way;
- Systems to enable the rapid and secure transfer of information around the system;
- Rapid communication between sectors at the time of key events (such as informing a GP of a patient's diagnosis or of their death within 24 hours of the event); and
- Enhancing the role of community teams in the management of cancer patients, as has been done in the Integrated Cancer Care Programme, through the appointment of care trackers and through enhancing the skills of community nurses.

## Psychological support

**5.33** Cancer patients and their families and carers may need psychological care and support. This can be as important as any other aspect of their treatment. Good psychological support services should be in place to support patients from the point of diagnosis and as they move along the patient pathway and progress their cancer journey.

**5.34** There are four key levels of psychological support:

- Level 1: Effective information giving, compassionate communication and general psychological support;
- Level 2: Psychological interventions, such as anxiety management, problem solving;
- Level 3: Counselling, theoretically driven psychological interventions, such as cognitive behavioural therapy and solution focused therapy; and
- Level 4: Specialist psychological and psychiatric interventions.

**5.35** Providing support for patients experiencing distress is a key component of the role of the CNS. Yet delivering this effectively will require appropriate training and support. Commissioners should work collaboratively to ensure that this is available.

**5.36** It is important for all service providers to have established pathways to enable patients to access specialist level three and four support as and when they need it. Commissioners will need to ensure that adequate provision is available so that all patients, families and carers can access the appropriate psychological support for them. This will include establishing service level agreements with local mental health services for more advanced support.

## Supportive and palliative care

**5.37** As discussed earlier in this chapter, implementing NICE guidance will significantly improve the quality of supportive and palliative care available to patients.

**5.38** The systematic reviews undertaken for the development of the NICE guidance revealed strengths and weaknesses in the worldwide evidence base related to supportive and palliative care. Research into patients' needs has been quite strong, but research into how best to meet those needs is lacking. As a result, NCRI set up two supportive and palliative care collaboratives, based around consortia of medical schools, hospitals and hospices. Five million pounds over five years of capacity-building grants has been allocated to these collaboratives and work began in 2006. The aim of the collaboratives is to develop the research infrastructure capacity for supportive and palliative care and through this leverage further research funding leading to the development of new, evidence based interventions.



### Box 30: Support for cancer patients

#### Maggie's Centres

Maggie's Centres are for anybody affected by cancer – not just people who have been diagnosed with cancer, but also their families, friends and carers.

Maggie's Centres help people achieve a psychologically healthy adjustment to their diagnosis and treatment. Maggie's programme of support comprises, one-to-one support with a clinical psychologist, facilitated group sessions, benefits advice, nutrition workshops, relaxation sessions and stress management courses and other activities including access to Maggie's information library. Maggie's programme is designed to give people the tools they need to cope with the upheaval cancer causes in their lives. Maggie's programme and drop in facility supplements the services available in hospitals, enabling them to provide a level of support that is beyond what is available in the health system. Maggie's Centres enable people to share experiences with others and with professional help, people are encouraged to address all aspects of living with cancer.

Maggie's Centres are free, not time limited and easily accessible. Maggie's Centres are built in close proximity to major cancer centres and cancer units.

There are five Maggie's Centres in Scotland, with a sixth centre planned. The London Maggie's Centre will open in early 2008 and further five centres are planned in Cotswolds, Nottingham, North East, South West Wales and Oxford. Throughout 2007, 58,000 visits were made to Maggie's Centres.

*"Walking into Maggie's was the best thing we ever did. It's a real oasis. You come out of Maggie's and get on with living"* Norrie Brown.

The domestic scale and imaginative environment of the centres are a key part of the Maggie's programme. Maggie's Centres are places for people to be themselves, not a hospital patient. ([www.maggiescentres.org](http://www.maggiescentres.org))

**5.39** It is important to recognise that there are a number of voluntary organisations and charities who provide high quality, innovative support services for cancer patients and survivors. An example of one is in Box 29.

**5.40** Patients with terminal cancer have particular supportive and palliative care needs as they reach the last year of their life. Providing opportunities to discuss the implications of entering the dying phase can improve the quality of life for both the patient and their carer. Such opportunities need to be handled with honesty and openness checking what the person understands, how much they wish to know and the extent to which other family members should be involved in their care. Exploring with the person their needs and preferences is paramount and will prevent unnecessary, inappropriate or prolonged treatment.

**5.41** Having established this relationship and assessed their needs and preferences, this needs to be reviewed at regular intervals, which will trigger the provision of other supportive and palliative care such as carer information or out of hours support information.

### The role of the Clinical Nurse Specialist

**5.42** During the development of this strategy patients repeatedly told us of the vital role that the clinical nurse specialist (CNS) can play in improving the experience of people living with and surviving cancer. Nurse specialists play a hugely valuable role across many different elements of cancer patient management and support, carrying out a range of technical, informational, emotional and coordination functions, including:

- Familial risk assessment;

- Communication and information;
- Delivering treatment (such as chemotherapy);
- Psychological and emotional support for patients and families;
- Providing continuity of care;
- Supporting and advising patients' families and carers; and
- Developing a post treatment plan.

5.43 Over the past decade there has been a significant expansion in the numbers of CNSs. However, there is more to do. For certain cancer types, upwards of 20% of MDTs currently do not have CNS cover. These include some lung, urology, gynaecology and upper GI teams.

5.44 Data indicate that substantial variation in the number of clinical nurse specialists available to support cancer patients at key points in the cancer pathway still exists across cancer networks.<sup>29</sup> There can be a significant variation in the provision of CNSs between cancer networks. This cannot simply be explained by geographical differences in cancer incidence or patient flows.

5.45 A recent report by the Prostate Cancer Charter for Action identified that there is also significant variation in provision of CNSs between different tumours, resulting in significant variations in the average caseload for a CNS.<sup>30</sup> For example, breast cancer and gynaecology nurse specialists have the lowest mean caseloads of 78 patients per whole time equivalent CNS and lung cancer and urology nurse specialists have the highest mean caseloads at 123 and 132 patients per whole time equivalent nurse respectively.<sup>31</sup> There are evident shortfalls in the number of clinical nurse specialists available to support patients with urological, lung and upper GI cancers.

5.46 The CNS' role may also need to adapt over time to reflect new treatments and care settings and changes in patient needs. Innovative solutions to improving patient experience should be explored such as the development of more

advanced practitioners and independent prescribers.

**5.47 Commissioners and providers should therefore give particular consideration to the role of clinical nurse specialists. Good commissioners will use the peer review data to benchmark their local CNS provision against that of similar PCTs and take action where the CNS workforce is found to be insufficient.**

### Training to improve the patient experience

5.48 All those involved in delivering care and support to cancer patients need appropriate training. **To deliver the vision set out in this chapter, it will be important to ensure that high quality training is available to equip healthcare professionals to:**

- **Deliver information to patients effectively;**
- **Work as part of an integrated multidisciplinary team;**
- **Engage in appropriate 'what if' conversations;**
- **To assess and manage/respond to the needs of cancer survivors; and**
- **In the case of CNSs, provide effective psychological support.**

5.49 Commissioners and providers will need to recognise the importance of this if they are to deliver improvements in the experience of people living with and surviving cancer. Chapter 11 sets out how we will approach training needs in the future.

### Helping patients meet the costs of cancer

5.50 Cancer can also significantly affect a person's finances. A Macmillan Cancer Support survey in 2006 found that 70% of cancer patients incurred travel costs. Based on the average number of trips, the cost per patient was estimated to be £325. Other costs to

patients include the cost of adjusting to disabilities caused by cancer or cancer treatment, prescription charges and the cost of home care. Estimates suggest that the cost of these to cancer patients could be around £200 a year.

5.51 The impact of cancer on patients is also felt through loss of earnings. The Macmillan survey indicated that 91% of cancer patients' households suffer a loss in income and/or increased costs as a direct result of cancer. Among under 55s, seven out of ten suffer a loss in household income, with an average fall of 50%.

### Access to benefits

5.52 Depending on their individual circumstances, cancer patients are entitled to the full range of social security benefits, including daily living costs and housing costs. In addition, special provision is made for terminally ill patients who may have their benefit claims processed more quickly. Special rules exist for some benefits to enable people who are terminally ill to be awarded higher amounts of some benefits. The parents of a child who is terminally ill can withdraw money from the Child Trust Fund without waiting until the child is 18. Those who care regularly and substantially for a severely disabled person may also be eligible to claim a carer's allowance.

5.53 There are a number of ways in which the Department of Health is working to support people in financial hardship with the costs associated with their healthcare. The NHS Low Income Scheme provides support for people in financial difficulties with prescription charges, dental treatment, sight tests and glasses and travel to receive NHS treatment through the Hospital Travel Costs Scheme.

5.54 What is clear, however, is that the majority of cancer patients are not aware of the support available to them. The 2005 National Audit Office report found that 77% of cancer patients are not given any financial support information.<sup>32</sup> We must therefore do more to support patients facing financial pressures as a result of their diagnosis. **As part of integrated services, commissioners should ensure that all people affected by cancer are given information about what financial help (including welfare benefits) is available and how to access that help and their rights under the Disability Discrimination Act. Information prescriptions would be an appropriate way of delivering this and information on financial benefits will be made available on the forthcoming national information pathways from 2008.**

### Box 31: Accessing information on financial help for patients

Macmillan Cancer Support has been developing a model for delivering benefit information and advice for people affected by cancer. This comprises:

- A network of local face-to-face advice services together with a national telephone helpline for people who need specialist advice and advocacy;
- A suite of printed and on-line financial information resources;
- A web based self assessment tool to help patients and carers identify potential benefit entitlement; and
- A web based e learning module to raise benefit awareness among health professionals and help them signpost patients and carers to advice services more effectively.

Macmillan aims to establish advice services in every PCT and has already developed 61 local services across England in partnership with Citizens Advice and other specialist advice providers.

Macmillan have estimated that in 2007, the combined impact of this model is that over £55 million in previously unclaimed benefits for patients and carers will have been identified and over 26,000 people helped with advice.

## Work and cancer

5.55 Cancer can have a profound impact on people's ability to work. Each year around 90,000 people of working age are diagnosed with cancer. Some of these will require protracted periods of time off work due to the impact of cancer and its treatment. Some may never be able to get back to work. However, for others continuing to work helps them to cope with what they are going through. An individually tailored approach is therefore needed.

5.56 From 2005, cancer patients have been protected by the Disability Discrimination Act from the point of diagnosis. The Act provides people with rights in a wide range of areas and places a duty on employers, providers of services, public authorities and transport providers not to discriminate against disabled people and make reasonable adjustments for them. In the area of employment, examples of reasonable adjustments might be allowing an employee with cancer time off for treatment or rehabilitation, or allowing them some flexibility in working hours or a phased return to work. Occupational Therapists play an important role in helping people return to their desired occupation. However further work is necessary to increase employers' awareness of the role of cancer within the Act. Although 80% of employers are aware of the Act, only 19% know that cancer is classed as a disability.<sup>33</sup>

5.57 A recent survey undertaken by Working with Cancer (a dedicated support group), Cancerbackup and the Chartered Institute of Personnel and Development highlighted the need for better advice on work related issues relating to cancer and its treatment. Cancerbackup and Working with Cancer have produced guidance for employers and employees. Guidance for carers will be published early in 2008.

**5.58 Commissioners should make sure that information for people who work and have cancer is made available to patients as soon as they are diagnosed. Advice on returning to work should be available for all patients of working age. Employers should be encouraged to support employees who wish to do so.**

## Surviving cancer

5.59 Macmillan Cancer Support defines a cancer survivor as someone who has completed initial treatment and has no apparent evidence of active disease, or is living with progressive disease and may be receiving treatment but is not in the terminal phase of illness, or someone who has had cancer in the past.

5.60 Survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs. At present services frequently do not meet these needs for patients or are poorly integrated. As many patients with cancer are elderly and have other medical problems, services for survivors need to be well integrated with those for other long term conditions. This is often best done by GPs and primary care services.

5.61 Problems relating to the after effects of treatment for cancer can, in some cases, be long lasting and severely debilitating. Examples include lymphoedema (swelling of a limb) following surgery and/or radiotherapy and brachial plexopathy, which can cause pain and weakness in an arm. Macmillan Cancer Support, with funding from the Department of Health is currently running an innovative pilot programme to assess how the needs for care of brachial plexopathy sufferers can best be met.

5.62 Follow up by a hospital team has for many years been considered to be a standard part of the management of a cancer patient. However patients frequently undergo follow up, both at a hospital and in primary care, but without good communication between the two, leading to duplication of effort and in some cases, confusion.

5.63 Hospital follow up is undertaken with several objectives. These include:

- Detection and management of acute complications or side effects of treatment;
- Early clinical detection of recurrence;
- Detection of late effects of treatment such as lymphoedema or secondary cancers;

- Psychological assessment and support; and
- To arrange surveillance investigations such as blood tests, CT scans and endoscopies.

5.64 In practice, follow up consultations are often brief, are conducted by relatively junior doctors and may not meet patients' needs.

5.65 Alternatives to hospital follow up have been successfully introduced in some places and for some cancer types. For example:

- Reducing the frequency of follow up in secondary care, meaning less visits to hospital;
- Transferring follow up to primary care according to predetermined protocols, so that appointments can happen closer to home;
- Nurse led follow up (in hospital or primary care); and
- Releasing patients from routine follow up, but giving them direct access back to the clinical team in relation to agreed "triggers".

5.66 Further detailed consideration now needs to be given to the services needed by survivors of cancer. **The National Cancer Director will lead a new National Cancer Survivorship Initiative to take this forward in partnership with Macmillan Cancer Support and other cancer charities.** This initiative will require collaboration between clinicians working in primary and secondary care, social care services, service users and patients and the voluntary sector. It will also link closely to ongoing work for patients with other long term conditions.

5.67 The National Cancer Survivorship Initiative will consider a range of approaches to survivorship care and how these can best be tailored to meet individual patients' needs. These include:

- Clinical follow up by hospital doctors, nurses and/or GPs (such as to detect recurrence and monitor late effects of treatment);

- Education, self care and expert patient programmes;
- Proactive case management, for example by telephone contact;
- Drop in centres for peer support;
- Automated surveillance systems to ensure tests are undertaken at appropriate intervals;
- Patient reports of wellbeing using electronic technology such as mobile phones;
- Provision of rehabilitation programmes;
- Psychological and spiritual support;
- Back to work support;
- Access to financial and benefits advice;
- Nutritional advice; and
- Ongoing support for carers.

5.68 The National Cancer Survivorship Initiative will also look in more detail at best practice regarding care planning for survivorship. This is likely to include formal assessments of a patient's needs and preferences for care at the completion of treatment and what role the patient wishes to take in managing their own care.

**5.69 As part of this work, Macmillan Cancer Support will host a think tank event, *Making the Cancer Survivorship Agenda a Reality*, in March 2008. The key outcomes of the event will be: to identify key policy work streams and priorities; to agree stakeholder involvement for each of the policy work streams; and to produce a report outlining the outcome of the event for wider circulation. The event will be co-chaired by the National Cancer Director and the CEO of Macmillan Cancer Support and will involve patients, health professionals, the voluntary sector, academics, research experts, international experts and the government.**

## Measurement of patients' experience of care

5.70 As we place a new emphasis on the quality of experience reported by people with cancer, it will be important that we are able to measure progress, tracking improvements in the qualitative as well as quantitative aspects of cancer care.

5.71 Large scale surveys of cancer patients undertaken in 2000 and in 2004 by the Department of Health and the National Audit Office demonstrated considerable improvements in relation to several aspects of patient experience. However, the 2004 survey also demonstrated that much more needed to be done. Prostate cancer patients continued to report a worse experience of care than those with breast, bowel and lung cancers and patients' experience of services in London remained less positive than elsewhere.

5.72 These large scale surveys demonstrate that cancer patients are prepared to complete detailed questionnaires which provide valuable snapshots about the experience of patients with different types of cancer and in different parts

of the country. The surveys have not, however, been major drivers of local service improvement, probably because there was little or no sense of local ownership of the process. In addition, little direction and support was given in how the findings could be used locally.

5.73 We therefore want to collect regular information on patients' experience and use this information locally to drive service improvements. **A new NHS Cancer Patient Experience Survey Programme will be established and surveys will be conducted annually. To take this forward an expert group, including patients, will be convened to design the technical specifications. A national contract will then be let for the collection, management and analysis of cancer patient experience surveys.**

This initiative will take full account of the Department of Health strategy review of customer experience information, which is being undertaken by PricewaterhouseCoopers and will be published in early 2008. The expert group will also consider the value of surveying carers of cancer patients.

**Figure 9: Improvement in Patients' Reports of their care between 2000 – 2004**

	2000	2004
Patients waiting less than one month to be seen by a specialist (irrespective of whether they were referred urgently)	70%	80%
Patients receiving written information at the time of diagnosis	45%	61%
Patients finding explanations of what was wrong with them very easy to understand	62%	68%
Patients fully understanding the purpose of the treatment	82%	86%
Patients who were given completely understandable explanations about side effects	63%	76%
Patients who were always treated with dignity and respect	79%	87%
Patients reporting that there were always enough doctors on duty	80%	84%
Patients reporting that there were always enough nurses on duty	75%	81%
Patients reporting confidence and trust in all of their doctors	87%	88%
Patients reporting confidence and trust in all of their nurses	79%	81%
Patients reporting that staff had done everything they could to relieve pain	81%	85%
Patients reporting a lot of confidence in the doctor seen at their most recent outpatient visit	68%	84%

5.74 The survey programme will enable the assessment of whether patients feel supported throughout their cancer journey, the extent to which their care is coordinated and more robust measurement of the impact that CNSs have on patient care.

5.75 Reliable measurement of the experience of care for patients managed by different teams and hospitals will allow:

- Patients to make informed choices about their care;
- Commissioners to ensure improvements in care through strong contract management;
- Local service providers to identify where improvements are most needed; and
- Local services to compare their performance with other services.

5.76 Throughout the development of this strategy experts have told us that commissioners and providers have sometimes found it difficult to give sufficient weight to actions which will improve patient experience in comparison with demands for new technologies. The NHS Cancer Patient Experience Survey Programme will provide commissioners with a mechanism to track the extent to which improvements are being delivered in this area. Chapters 8 and 9 set out how they may wish to use this information to work with providers to deliver improvements.

## Chapter 6: Reducing cancer inequalities

### Chapter Summary

- Inequalities in cancer outcomes are experienced by a range of different groups in society including socio economically deprived groups, black and minority ethnic groups, older or younger people, men or women, people with disabilities, people from particular religions or with particular beliefs and gays, lesbians or bisexuals. Inequalities may vary according to the type of cancer as well as other factors such as location;
- Although the inequalities gap between the most deprived groups and the general population has got smaller, more needs to be done to tackle inequalities as experienced by all these different groups;
- Priority should be given to action to reduce smoking among groups with a high smoking prevalence and to increase awareness of the risk factors and symptoms for cancer among groups with low awareness; and
- We will begin a National Cancer Equality Initiative, bringing together key stakeholders from the professions, voluntary sector and academia to develop research proposals on cancer inequalities, test interventions and advise on the development of wider policy.

### Introduction

**6.1** The Cancer Reform Strategy has been subject to an Equality Impact Assessment which shows that there will be no overall adverse effect on inequalities as a result of the measures for cancer that we are introducing. However, we want this strategy to go much further than that, achieving a substantial reduction in inequalities in cancer. One of the key aims of the Cancer Reform Strategy is to reduce inequalities in cancer incidence and increase access to high quality cancer care and cancer outcomes.

**6.2** Inequalities may be experienced by a range of different groups within society. These include:

- Socio economically deprived groups;
- Black and minority (BME) ethnic groups;
- Older or younger people;

- Men or women;
- People with disabilities;
- People from particular religions or with particular beliefs; and
- Gays, lesbians or bisexuals.

**6.3** There are multiple potential sources of inequality relating to cancer, which can impact on incidence, survival, mortality, patient experience or quality of life. These include:

- Exposure to infections linked to cancer;
- Genetic risk of developing cancer;
- Awareness and attitude to lifestyle risk factors for cancer;
- Uptake of prevention and screening services;



- Access to diagnostic and treatment services; and
- Provision of information and support.

**6.4** This chapter outlines how the different announcements and recommendations in the Cancer Reform Strategy will impact on inequalities and also sets out an overview of some of the major causes of cancer inequality together with recommendations for local action to reduce these inequalities.

### The impact of the Cancer Reform Strategy on inequalities

**6.5** The Cancer Reform Strategy includes a number of actions which should help reduce inequalities:

- Action on smoking will particularly benefit groups in society with higher rates of smoking prevalence, such as manual workers and some BME communities;
- Measures to ensure faster referral and diagnosis for people where cancer is suspected will help those who may be less informed about cancer signs and symptoms;
- Reducing cancer waits will enable faster treatment for all patients;
- Expanding radiotherapy capacity will reduce inequalities in the availability of a treatment which benefits over half of all patients with cancer;
- A commitment that as a default position new cancer drugs and significant new licensed indications will normally be referred to NICE and to ensure that NICE appraisal guidance is available as early as possible;
- Improved information and a new focus on improving the experience of cancer patients will ensure that all patients are given the appropriate information, advice and support throughout their cancer journey; and
- Greater help for people who have survived or are living with cancer, including better

psychological support, assistance with getting back to work or claiming the financial support to which they are entitled, will help more economically deprived groups in society.

**6.6** However, we also recognise that some of the measures we are taking may, at least initially, widen inequalities:

- Measures to improve awareness of prevention messages as well as the signs and symptoms of cancer are likely to be disproportionately acted upon by the informed and articulate;
- Expanding screening will benefit everyone who is eligible, but groups with lower levels of uptake will experience less benefit; and
- Affluent and articulate people are more likely to make immediate use of information about the performance of hospitals.

### Further national action to tackle inequalities

**6.7** A major challenge in reducing inequalities in cancer is the lack of evidence about the extent to which different forms of inequalities exist, what causes them and what interventions will be most effective in addressing them.

**6.8 In recognition of this challenge we will begin a National Cancer Equality Initiative, bringing together key stakeholders from the professions, voluntary sector, academia and equality groups to develop research proposals on cancer inequalities, test interventions and advise on the development of wider policy. The National Cancer Equality Initiative will initially focus on:**

- **Optimising data collection to enhance our understanding of the inequalities that exist;**
- **Promoting research to fill gaps in the evidence; and**
- **Spreading good practice.**

**6.9 The Department of Health will also work through the National Cancer Equality Initiative with Strategic Health Authorities (SHAs) and Primary Care Trusts (PCTs) to agree challenging goals for reducing cancer mortality in every cancer network area by 2012. These goals will pay particular attention to tackling the different forms of inequality set out in this chapter, as a means to reducing overall mortality. The progress made by each PCT, cooperating through the cancer network, in meeting these goals will form an important part of our ongoing action to reduce cancer inequalities.**

6.10 The National Audit Office is funding a dedicated post in the Cancer Action Team to drive forward equity issues. This person will work closely with the National Cancer Director in developing the National Cancer Equality Initiative.

**6.11 The Department of Health will also continue to encourage innovation in tackling inequalities through its Section 64 grant programme.** Currently 36 percent of grants on cancer programmes address equality issues.<sup>34</sup>

6.12 The UK National Screening Committee is conducting an equality review within the national screening programmes, including those for cancer. As a result of this review, the UK National screening Committee will consider what initiatives could be undertaken to improve access to screening in vulnerable populations.

## Types of cancer inequality and recommendations for local action

**6.13 Local action will also be necessary to tackle inequalities. As part of the measures we are introducing to ensure stronger commissioning, PCTs, in association with their cancer network, will wish to undertake a local equality impact assessment and take appropriate steps to address local issues.**

6.14 This assessment should include assessing screening coverage rates amongst groups with

particularly poor cancer outcomes and setting out plans to improve screening coverage.

6.15 If inequalities in cancer are to be reduced, it will be important to understand the nature of the inequalities that different groups face. Further research into this will be a priority but good commissioners should take into account the existing evidence, which is summarised below.

## Socio economic deprivation and cancer

6.16 Socio economic deprivation has a marked impact on cancer outcomes. Cancer mortality is more than 15% higher in 'spearhead' PCTs than the national average. Although mortality from cancer is falling across the country as a whole and in spearhead PCTs, the gap remains wide.

6.17 The increased mortality in deprived groups can largely be attributed to:

- Higher smoking rates. Research has shown that the substantial social inequalities in adult male mortality during the 1990s were due to the effects of smoking. Stopping smoking could eventually halve this difference.<sup>35</sup> Smoking leads to higher mortality rates from poor prognosis cancers such as lung and oesophagus; and
- Low awareness of cancer and the benefits of early detection, leading to lower uptake of screening opportunities and later presentation with symptoms when cancer develops.<sup>36</sup>

6.18 The actions set out in chapters 2 and 3 of this strategy are intended to help address these underlying causes of inequality.

6.19 The government has a Public Service Agreement 'to reduce inequalities in health outcomes by ten percent by 2010 as measured by infant mortality and life expectancy at birth'. For life expectancy this means 'by 2010 to reduce by at least ten per cent the gap between the fifth of local authority areas with the lowest life expectancy at birth and the population as a whole'. Reducing inequalities in cancer will play a major part in achieving this goal. The Department of Health will continue to monitor the gap in

mortality, as well as differences in one and five year survival.

### Race and cancer

**6.20** The links between race and cancer are complex and differ between different black and minority ethnic populations. Our understanding of these links has been hampered in the past by poor recording of ethnicity within the NHS, but this is now improving.

**6.21** It is important to recognise that many BME populations in England have a younger age profile than the white British population and have not, therefore, yet reached the age when cancer is most common. However, the needs of different generations within communities may be very different and will need to be planned for.

**6.22** The incidence of cancer varies between ethnic groups. For example, compared to the general population:

- Prostate cancer incidence is higher in African Caribbean men;
- Mouth cancer incidence is higher amongst South Asians; and

- Liver cancer incidence is higher among Bangladeshis and Chinese.

**6.23** Some of these differences are due to lifestyle factors and exposure to infections. Others may be caused by genetic factors.

**6.24** Different BME communities will have different needs and it is important that a personalised NHS is able to meet them. We set out in the Department of Health's Single Equality Scheme the actions which we will be taking to ensure that the NHS is equipped to meet the needs of cancer patients from different communities, including:

- Developing a model for best practice guidance within cancer networks by 2009;
- Improving ethnic monitoring of cancer patients through cancer registries by 2008;
- Providing a forum for stakeholders working with BME communities and charities to share best practice and evaluation of projects undertaken by 2008; and
- Providing a range of screening leaflets in various languages and audio visual aids.

#### Box 32: Providing culturally appropriate information

People from BME communities come later to diagnosis, are under-represented in clinical trials and are less likely to access palliative care services. Some cancers are more common among particular BME groups. Cultural, religious and social factors affect the delivery of information and treatment; cancer may be seen as a punishment, an infection, or simply not exist as a concept, there being no word for cancer in some languages. There may be a distrust of "western" medicine and a reliance on healing through prayer or traditional medicines. Over one million people in the UK do not have English as a first language and many struggle to receive complex information on cancer, even when they speak English adequately for day-to-day purposes.

Cancerbackup's helpline allows people to speak to a specialist cancer nurse in over 100 languages through an interpreter, with direct access lines for speakers of the twelve most common community languages. It has produced written and videotaped cancer information in Turkish, Cantonese and six Asian languages and holds a database of resources in other languages. Medical and community advisers have compiled answers to 120 culturally-sensitive questions about cancer frequently asked by BME communities. These are posted on Cancerbackup's main website and available to health professionals. The specialist cancer information nurses in London and at Cancerbackup's local information Centres work with specially trained interpreters to undertake outreach work with local communities.

**6.25** Patient experience surveys have shown that BME groups, in general, report a worse experience of treatment and care. The actions set out in chapter 5 are intended to help address this.

**6.26** As we move forward it will be important to assess the impact of newer trends in migration, ensuring that cancer services are equipped to meet the needs of different populations. For example, many migrant communities from Eastern Europe have higher rates of smoking which may require specific local action. Good commissioners will consider the needs of all the groups they serve and develop strategies to address these.

### Age and cancer

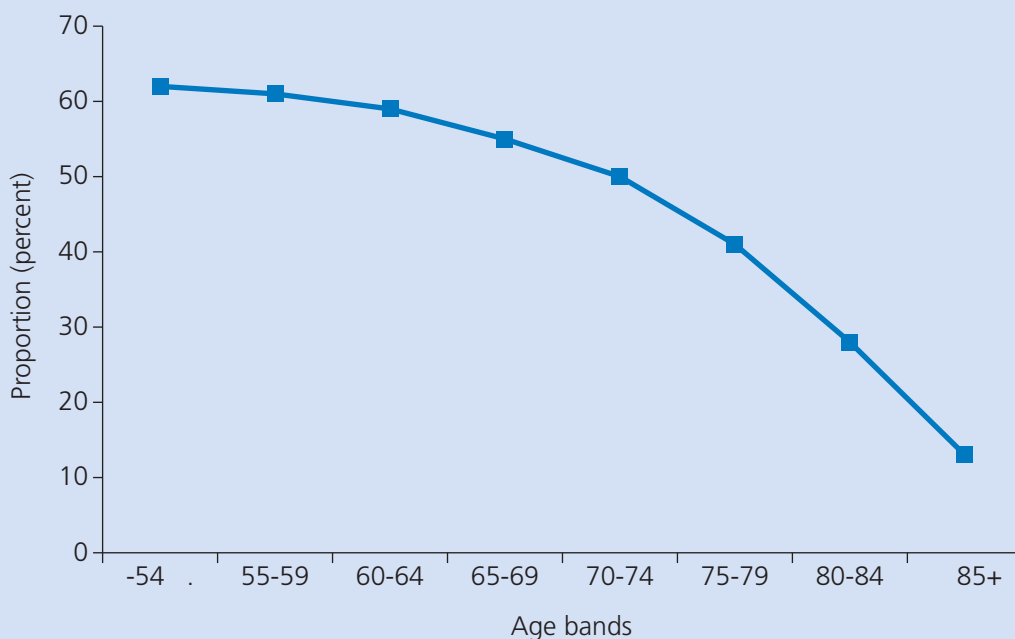
**6.27** Cancer predominantly affects older people. Fifty one percent of all cancer diagnosed is in people over 70 years old and more than three quarters of all cancer deaths occur in people aged over 65 years.

**6.28** The link between increasing age and increasing risk of developing cancer appears to be poorly understood by the public. For example a recent study by the NHS Cancer Screening Research Group found that over 50% of women wrongly believe that the risk of breast cancer does not vary with age, with only one per cent correctly believing that the oldest women are at greatest risk.<sup>37</sup> Lack of awareness that they are still at risk of developing breast cancer appears to be one of the major reasons why older women with breast cancer present later and with more advanced disease than younger women.

**6.29** The information we will collect on awareness, clinical outcomes and patient experience will be a powerful tool for identifying areas where further work is necessary if older people are to benefit from the best possible cancer services.

**6.30** There is some evidence that older people receive less intensive treatment than younger

**Figure 10: Proportion of patients in England and Wales in the various age bands who received any active anti-cancer treatment**



Data from the second annual report of the national lung cancer audit programme

people even when they are fit enough to do so. Evidence recently published in the British Journal of Cancer suggests that, even after adjusting for tumour type, when compared to younger women older women are less likely to receive standard management for breast cancer, such as radiotherapy treatment.<sup>38</sup> Similarly, data gathered from the national lung cancer audit suggests that older people are less likely to receive radical treatment (Figure 10)<sup>39</sup>. Experts in the care of older people will be invited to join the National Cancer Equality Initiative to advise on this.

**6.31** Most clinical trials focus on patients under the age of 65, meaning that less data are available on the efficacy of treatment in older people. We believe that later stage trials should be conducted in groups who would be most likely to be treated with the medicines in question. **We will work with the NCRN to develop ways of encouraging more clinical trials to include older people. We will also encourage medicines' regulators and**

**industry to work together so that the use of age as an exclusion criterion in cancer clinical trials is avoided wherever possible.**

**6.32** In the meantime, we do not believe that age should be used as a barrier to treatment. The assumption should be that older patients should receive the same level of treatment. The only acceptable criteria for not giving a clinically appropriate and cost effective treatment should be poor patient health or a patient themselves making a choice not to receive further treatment. We will explore ways of making this more explicit when guidance is issued on interventions where clinical trials may have excluded older people.

**6.33** The majority of children have the opportunity to participate in clinical trials and this should continue. However, the situation is less impressive for teenagers and young adults. Over 70% of attendees at a recent Teenage Cancer Trust conference reported that they were

### Box 33: Age appropriate services

The Christie Teenage Cancer Unit is one of a number of units in the country, supported by the Teenage Cancer Trust, that cares specifically for teenagers & young adults with cancer, a distinct group with unique needs that differ from both children and adults. The unit is aimed at 16-24 year olds and currently has 13 beds plus a day service. It provides a hospital environment that is appropriate to young people including internet access per bed, allowance of mobile phones and access to music equipment, Sky TV etc. There is also access to space for socialising and space to meet the needs of families, siblings and carers.

A diagnosis of cancer in this age group results in complex psychosocial issues for both the patients and their families/carers. Young people at the Christie are therefore cared for by staff with extensive knowledge and expertise in cancer in this age group – staff with knowledge of a young person's cancer journey, typical reactions of young people facing cancer, young people's coping mechanisms, excellent communication/interpersonal skills and the ability to recognize psychological problems/dysfunction in young people to ensure early/timely intervention.

Extensive support services are also offered led by a Support and Activity Coordinator. Support groups are available to young people throughout treatment; from diagnosis and for many years after treatment. These groups ensure that young people remain socially motivated, continue to function as young people, have access to their peer group, support from other patients and aid the transition process back to 'normality' once treatment is completed. There is also a teenage & young adult community liaison post to bridge the gap between children's and adult existing community services/teams and to offer expert advice regarding care for this group to existing community staff and ensure that young people with cancer are offered support at home whilst undergoing cancer treatment. In addition the unit has a lead teenage & young adult nurse to drive and coordinate the services offered.

not offered the chance to be treated in clinical trials. Implementation of the Improving Outcomes Guidance on Children & Young People with Cancer should ensure that children & young people, are treated in centres where a complete portfolio of relevant trials is supported.

**6.34** Children and younger people who develop cancer will have very different needs and it will be important that care for them is provided in an age appropriate setting. For teenagers and young adults with cancer, it is estimated that 70% are not treated in a setting appropriate for their age. Implementation of the Children and Young People's Improving Outcomes Guidance (IOG) will therefore require provision of a sufficient number of dedicated age appropriate services to ensure that every network has a service to refer to. More than one service may be needed in high density populations. Good commissioners will ensure that services are age appropriate for the population they serve.

## Gender and cancer

**6.35** Some cancers are gender specific (such as prostate and testicular for men, ovary and uterus for women) and others affect one gender far more than the other (such as breast cancer). However, for the ten commonest cancers which affect both men and women age standardised mortality rates are in every case higher in men.

**6.36** The reasons for the differences in mortality rates between men and women are not fully understood. In some cancers, such as lung cancer and oesophageal cancer, differences in smoking prevalence play a large part. In some other cancers, it may be due to later presentation by men. In melanoma for example, the incidence is higher in women, possibly because of the greater over exposure to sunlight, but death rates are higher in men, perhaps due to presentation at a more advanced stage.

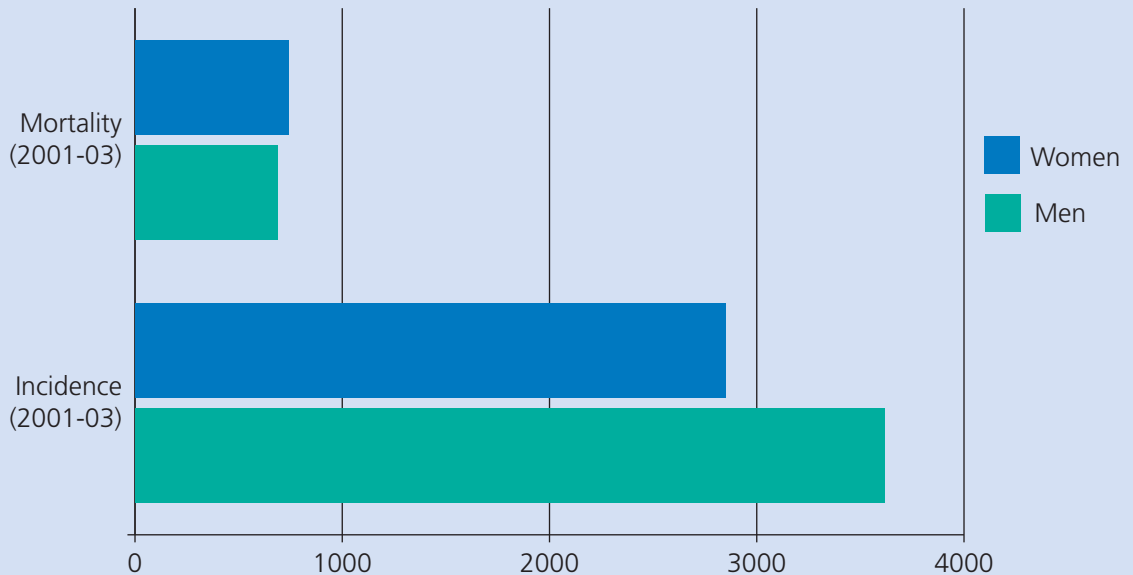
**6.37** In 2006, a symposium organised by the Men's Health Forum and chaired by the National Cancer Director discussed the issues around cancer and gender. The event highlighted that there are still many cancer types for which the reason for higher incidence and mortality in men is not known and that this higher incidence may be the result of unidentified risk factors or general biological predisposition.<sup>40</sup> It is clear that more research is needed if we are to fully understand how gender impacts on cancer.

**6.38** The Symposium also highlighted that the range of settings in which men are offered advice, information and routine health checks should be expanded from traditional primary and secondary care settings, for example into the workplace.

**Figure 11: Age standardised mortality per 100,000 population**

	Men	Women
Lung	55.8	28.4
Colorectal	24.0	14.7
Oesophagus	13.0	5.1
Stomach	10.9	4.3
Pancreas	9.6	7.3
Bladder	9.1	3.0
Non-Hodgkin's Lymphoma	7.5	4.7
Leukaemia	6.8	4.3
Kidney	6.1	2.3
Melanoma	2.7	1.9

**Figure 12: Comparison of incidence and mortality of melanoma in men and women in England**



### Disability and cancer

**6.39** For people with disabilities, cancer can pose particular challenges. For example, although people with learning disabilities have a similar overall risk of cancer to the rest of the population, they nonetheless have a higher risk of some cancers such as cancer of the gall bladder and thyroid gland and leukaemia, but a lower risk of prostate, lung and urinary tract cancers.<sup>41</sup>

**6.40** There is also evidence that uptake of screening is low amongst people with learning disabilities. Figures for breast screening in 1998 showed 43% average uptake for those women with learning disabilities compared to 76% for women overall. For cervical screening the figures were three per cent and 85% respectively.<sup>42</sup> There are also distressing stories of people with learning disabilities getting poor access to services when they do have symptoms of cancer.

#### Box 34: Emma's story

Emma, aged 26, had a severe learning disability, which meant that she sometimes displayed challenging behaviour and had difficulty in communicating how she felt.

Emma had not eaten for eight days and was feeling unwell. Her mother took her to her GP who diagnosed a virus. A further visit to a different GP resulted in Emma being sent for hospital tests. Despite Emma being in pain, the hospital did not prescribe painkillers as they claimed Emma was refusing to consent to treatment.

The tests showed that Emma had cancer which was treatable. Clinicians however decided that Emma was not able to consent to treatment and did not treat her, or offer her pain relief. Emma's mother took legal action but by that stage the cancer had advanced too far to be treated.

Emma was admitted to a hospice and died a month later.<sup>43</sup>

## Religion or belief and cancer

**6.41** It can sometimes be difficult to separate out factors relating to religion or belief from other cultural and socioeconomic factors. However, attitudes to cancer may differ between religions, potentially contributing to variations in uptake of screening, stage of presentation and attitudes towards treatment.

**6.42** Stronger commissioning will involve planning services which are appropriate to the needs and culture of local communities. Commissioners should therefore take into account religious beliefs when designing services.

## Sexual orientation and cancer

**6.43** Homosexual and bisexual populations can have elevated risk factors for some cancers. For example, smoking rates amongst homosexual and bisexual populations are much higher (41%) than the national average (24%). Homosexual men have a raised risk of anal cancer, related to infection with the Human Papilloma Virus (HPV). They also have a higher rate of Kaposi Sarcoma and non-Hodgkin's Lymphoma related to HIV/AIDS. Lesbians may be at higher risk of breast cancer as they are less likely to have the protective effect of pregnancy. There is also evidence to suggest that they are less likely to take up screening<sup>44</sup>.

**6.44** PCTs with high homosexual, lesbian and bisexual populations may wish to consider targeted awareness-raising initiatives to address these issues.



## Chapter 7: Delivering care in the most appropriate setting

### Chapter Summary

- New models of care can bring significant advantages to patients and release resources for other developments;
- PCTs will wish to ensure that GPs have appropriate and timely access to diagnostic tests. This will reduce delays in diagnosis and should reduce unnecessary referrals to hospital;
- Some specialised diagnostic tests should be provided at cancer network level;
- Cancer inpatient care can be streamlined, with benefits for patients and the NHS. Commissioners will wish to give this high priority; and
- An End of Life Care Strategy will be published in 2008. In the meantime PCTs will wish to apply lessons learned from the baseline reviews undertaken in 2007/08 to commissioning decisions for 2008/09.

### Introduction

7.1 Much of the focus in the past decade has been on reducing hospital waits and ensuring that patients have access to specialists with the necessary expertise to deliver high quality cancer treatment. To do this, new models of care have been widely introduced across the country through:

- Rapid access clinics in District General Hospitals;
- Multidisciplinary teams, some of which are in District General Hospitals and some in cancer centres; and
- Ensuring that complex treatments are undertaken by specialist teams.

7.2 The Cancer Reform Strategy looks more widely across the care pathway, encompassing: investigation prior to diagnosis; full assessment and treatment planning once the diagnosis of cancer is established; primary treatment,

including inpatient care; support following the completion of primary treatment; management of recurrence and late-effects of cancer treatment; and end-of-life care.

7.3 Service models need to be developed which meet the needs of patients at each step in their care pathway and which are cost-effective. As acknowledged in the interim report of the NHS Next Stage Review, patients rightly expect that their services are safe, fair, effective and personalised.<sup>45</sup>

7.4 This chapter sets out some of the changes to cancer service models that commissioners should consider. These are:

- Increasing access to diagnostics;
- Improving service models for inpatient care, in particular minimising lengths of stay in hospital and preventing unnecessary hospital admissions;

- Ensuring multidisciplinary team working; and
- Providing more choice in end of life care.

7.5 A theme of many of these service models is to provide care outside of hospital settings where possible, with efficient access to hospital services when necessary. Most cancer patients want to receive as much of their care as possible close to home. However, they also recognise that they may have to travel to see a specialist team to receive the highest possible quality of care, especially for complex investigations or treatments.

**7.6 In all cases, commissioners should ensure that any satellite services developed outside hospitals, whether in diagnostics, radiotherapy or chemotherapy, are fully integrated with other services within the cancer network. Good links will ensure the highest standards of clinical governance, standardised protocols and a streamlined pathway for patients navigating between out-of-hospital and hospital care.**

### Access to diagnostics

7.7 Several of the expert groups which advised on this strategy agreed that increasing access to diagnostic tests was an important need in cancer services. Diagnostics are important at four levels:

- To help GPs quickly and conveniently exclude a cancer diagnosis in people whom they judge that the chance is low that their symptoms are due to cancer;
- To ensure that patients with a high chance of having cancer are given the right high-quality specialist diagnostic tests to diagnose their cancer quickly;
- To support the monitoring and management of cancer patients throughout their treatment, for example to assess how a tumour is responding to a particular treatment; and
- To detect or exclude recurrence for patients who are in remission.

### Increasing access to diagnostics from primary care

7.8 As discussed in chapter 3, GPs and primary care professionals should have quick and easy access to relevant diagnostic tests to exclude cancer in patients at low risk.

7.9 GPs have for many years had direct access to blood tests and to simple imaging tests such as chest x-rays. In some parts of the country GPs now have access, subject to agreed protocols, to a much wider range of diagnostic tests which can help to confirm or exclude cancer. These include:

- Endoscopy services;
- Non-obstetric ultrasound;
- CT scanning; and
- MRI.

7.10 Increasing use of independent diagnostics providers has helped improve capacity for MRI, with approximately 90,000 scans per annum being provided to NHS patients by Alliance Medical through the term of the MRI fastrack contract.

7.11 However, timely access to such services is not universal. Patients who would benefit from investigation may either not be investigated at all or may be referred to secondary care just to get an investigation done. As a result patients are almost certainly under investigated for cancer, but over-referred. Under investigation can lead to delayed diagnosis with catastrophic results for individual patients.

**7.12 A good Primary Care Trust (PCT) will wish to ensure that primary care professionals have appropriate and timely direct access to diagnostic tests. They may wish to take account of good practice recommendations developed by the Royal Colleges of Radiologists and General Practitioners.<sup>46</sup> The PCT will also wish to consider whether these diagnostic facilities should be provided in acute general hospitals or in community settings.**

**7.13** GPs with a special interest in cancer may wish to develop and offer particular diagnostic services under practice based commissioning. During the development of this strategy stakeholders told us that models which may develop and will need to be evaluated include:

- Community-based Prostate Health Clinics (see Box 35 below); and
- Genetics services (see chapter 2).

### Specialist diagnostic services

**7.14** If a GP suspects that a patient has a high chance of cancer, the patient should be referred to a specialist diagnostic unit, linked to an MDT under the two week wait standard. Where clinically appropriate, these units should offer all necessary diagnostic tests in one visit, with same day results. These units would provide the latest technology and be staffed by experts in interpreting cancer diagnostic information. This would ensure continuity of care and facilitate multidisciplinary working.

**7.15** For some cancers highly specialised diagnostic facilities are required either for diagnosis (such as molecular pathology) or for

determining the extent of disease (such as PET-CT scanning). These services may require high levels of expertise for accurate investigation and in some cases, expensive technology. It will not be appropriate for all hospitals to provide these services. The Leeds haematological diagnostic service provides a model for the delivery of complex diagnostic services for a population of almost four million people (see box 36 overleaf).

**7.16** The Leeds haematological service has also pioneered a patient-centred monitoring service in response to the increased number of patients diagnosed with haematological malignancy not requiring immediate treatment. The service is community-based using primary care phlebotomy and central haematological review of laboratory parameters, with symptoms identified by a patient self-assessment questionnaire. This approach is effective at identifying patients in need of treatment and results in improved access and convenience with less travel for patients and significantly reduced waiting times. Patients are supplied with copies of all relevant information and have access to telephone advice empowering them to manage their condition.

#### Box 35: Community-based Prostate Health Clinics

Due to the complexities involved in diagnosing significant prostate cancers, one suggested model is that men should receive advice and support on prostate health issues at dedicated community-based prostate health clinics. Decision advisers would help men at the following points in the pathway:

- Men without symptoms considering having a PSA test or equivalent;
- Men with urinary or other potential symptoms of prostate cancer;
- Men considering having a biopsy for prostate cancer following a PSA test; and
- Men diagnosed with benign prostate disease.

Decision advisers could be clinical nurse specialists (CNSs) on a dedicated or outreach basis, GPs with a special interest in prostate cancer, community based specialist urologists or other appropriately trained practitioners. Access to prostate health clinics would be via GP referral or direct access for men concerned about their prostate health.

Improved support for men in making decisions about further investigation or treatment would not be a form of rationing, but rather a way of ensuring that men have the best possible information and support when making difficult decisions. Improved support for men will ensure that more appropriate referrals for biopsy or further care will be made, reducing unnecessary interventions and complications, saving significant levels of NHS resources.

### Box 36: The Leeds haematological malignancy diagnostic service

Although each of the individual haematological malignancies is relatively rare, collectively they account for about ten percent of all cancers. Accurate diagnosis and classification of haematological malignancy is clinically critical and determines the selection of treatment. This may range from observation only through to intensive chemotherapy and bone marrow transplantation. Evidence from published studies, audits and clinical trial reviews suggests that there is a problem with existing approaches to diagnosis with a misdiagnosis rate of lymphoid malignancies of 10-20% leading to adverse clinical outcomes.

Accurate diagnosis of haematological malignancy depends on the use of a range of diagnostic methods including immunophenotyping, morphological examination and molecular genetics. In many service models these diagnostic techniques are provided by several different pathology departments. As well as potentially wasteful duplication of resources, this model does not exploit the power of cross validation of the results of individual diagnostic tests in ensuring the accuracy of the final diagnosis or provide a formal mechanism to resolve apparently contradictory results generated in different laboratories. The Haematological Malignancy Diagnostic Service (HMDS), based in Leeds Teaching Hospitals, provides a specialist diagnostic service for Haematological Oncology in North and West Yorkshire and Humberside. The laboratory includes the full range of diagnostic technologies and this allows the use of integrated investigative protocols that exploit the strength of individual techniques to ensure the quality and accuracy of the final interpretative report. By serving a large population of almost four million, HMDS has been able to bring together the specialist expertise and capital resources that are required to cost effectively provide this type of service. The concentration of specialist staff and resources ensure a fast specimen reporting time and 24 hour availability.

The basic concepts and technology underpinning the diagnosis and treatment of haematological malignancy are changing rapidly. As a fully integrated laboratory, embedded in the clinical network, HMDS can respond quickly to clinical innovation and promote development of the clinical service as a whole. This is difficult for laboratories based around a single technique serving a wide range of clinical specialities. As the sole diagnostic laboratory serving a large network HMDS is able to act as a hub for clinical data collection on which effective audit and accurate epidemiology are based.

**7.17 PCTs working together across a cancer network will wish to consider which diagnostic services should be centralised, taking account of National Institute for Health and Clinical Excellence (NICE) Improving Outcomes Guidance. They will also wish to consider what follow up services could be provided closer to peoples' homes, but with appropriate specialist monitoring.**

#### Inpatient care

**7.18** Inpatient care for patients diagnosed with cancer accounts for around twelve percent of all inpatient bed days in England. Cancer patients occupy a total of around 5.3 million bed days a year. This equates to around 14,550 cancer patients being in a hospital bed on any one day.

A typical cancer network servicing a population of 1.5 million would therefore have around 440 cancer patients in hospital at any one time.

**7.19** Over the past eight years inpatient admissions for cancer have risen by 25% from around 625,000 to 785,000 per annum. Most of this increase relates to emergency inpatient episodes, which have increased by 47%, while elective inpatient episodes have increased by 8.6%. A large proportion of emergency admissions for cancer are managed by physicians in general medicine or geriatricians. Over the same time period elective day case episodes have risen by 50% (from around 520,000 per annum to around 780,000 per annum).

7.20 The increase in cancer inpatient admissions has to a certain extent been offset by a reduction in average lengths of stay. Overall bed days have risen by one percent per annum. Elective bed days have reduced by around one percent per annum, with emergency bed days rising by around 2.5% per annum.

7.21 Given the projected increase in incidence of cancer and the age profile of cancer patients it can be anticipated that bed utilisation for cancer will continue to rise year on year, unless appropriate action is taken.

7.22 Going forward, cancer incidence in England is projected to increase by 25% over the next 15 years, mostly due to the anticipated effects of population growth and ageing.<sup>47</sup> Department of Health analysis suggests that, unless actions are taken to reduce lengths of stays and unnecessary admissions, inpatient costs for cancer are expected to increase by 24% in the same period. The increase will differentially affect certain groups. For example, inpatient costs for the over 70s are expected to increase by 37% compared to 13% for the under 70s.

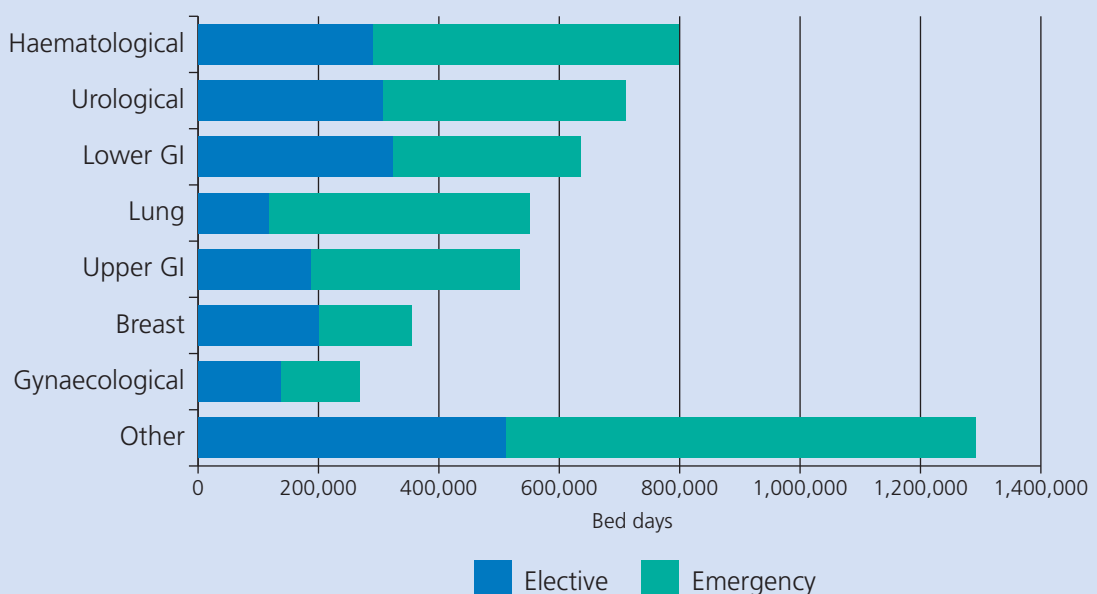
7.23 In order to keep inpatient costs at current levels, it is estimated that average lengths of stay would need to reduce by about a third, or alternatively, emergency admissions per cancer patient would need to reduce to almost 50% of their current levels. These are ambitious aims, but, as the next section demonstrates, they are within the possible scope for efficiency gains suggested by numerous different studies on inpatient care.

7.24 Figure 13 below shows how inpatient bed days vary by cancer type. Admissions for cancer are spread across many different specialities and vary between tumour groups. Around 60% of all cancer bed days relate to non-elective admissions.

### Evidence of opportunities to improve inpatient care

7.25 A total of 40 pilots, led by the Cancer Services Collaborative Improvement Partnership, are now underway within the NHS looking at ways of improving different aspects of cancer inpatient care. The seven pilots in the first wave of this programme have been highly successful (see examples in Boxes 37 and 39) and the more recent pilots are showing great promise.

Figure 13: Bed occupancy by cancer type<sup>48</sup>



**7.26** In the year leading up to the Cancer Reform Strategy, the Cancer Services Collaborative Improvement Partnership, Cancer Action Team and the NHS Institute have conducted a number of studies and pilots looking at ways to improve inpatient care and this work has identified huge potential to improve the quality and productivity of inpatient care for cancer and reduce unnecessary hospital use.

**7.27** In particular, this work has provided valuable evidence of three ways in which inpatient services can be improved for cancer:

- Minimising lengths of stay in hospital for medical and surgical admissions;
- Preventing unnecessary hospital admissions; and
- Bringing services together in an ambulatory care model.

**7.28** A study by the Cancer Action Team in collaboration with Aptium Oncology has revealed that patients hospitalised for cancer in this country would have been managed differently in the US, with lower bed utilisation. Cases were reviewed to establish whether inpatient stays could be reduced in length or avoided altogether. It was suggested that had the Aptium ambulatory care model been applied, over one-third of hospital admissions could have been avoided and over one-third of stays made shorter.

**7.29** Many medical issues associated with cancer do not require hospital admission and can be managed in other ways. 'Ambulatory care' is care delivered on an outpatient basis. Many medical investigations can be performed on an ambulatory basis, including blood tests, x-rays, endoscopy and some biopsy procedures.

**7.30** When designing and planning service models for cancer, this model of care presents significant opportunities. Outpatient centres could bring together assessment units, diagnostic

services and treatment services, together with supportive and palliative care such as symptom control and psychological and social care support.

**7.31** Advances in drug therapies mean that many cancer patients no longer have to stay in hospital as inpatients. With the exception of complex haematological treatments, almost all chemotherapy treatments could be delivered in an ambulatory care setting and some patients can even take their medication at home. Medicines to control the adverse symptoms of chemotherapy such as neutropenic fever and vomiting are much improved and the use of these, combined with better patient education about symptoms, should make emergency admissions due to side effects of treatment a rare event. If problems arise, the aim should be to manage them in ambulatory care without the need for admission via A&E.

**7.32** This model of care has been developed in the United States. Clinicians who are familiar with these services are convinced that they provide better care for patients and lead to reduced inpatient admissions. In a survey conducted by Aptium, almost all patients presenting to the ambulatory care centre with rapidly accelerating or acutely uncontrolled cancer-related pain were able to be managed without admission.<sup>49</sup>

**7.33** Patients who took part in the early Cancer Services Collaborative pilots said that they preferred being in hospital for shorter periods of time as a quicker return home meant that they were able to get back to normal life more quickly, to be independent, return to work earlier and be with their families.

**7.34** Four key principles have emerged from these pilots:

- Unscheduled (emergency) patients should be assessed prior to the decision to admit. No patient should be admitted without a clear reason;

- Patients should be on defined inpatient pathways based on their tumour type and the reason for admission;
- Clinical decisions should be made on a daily basis to promote proactive case management; and
- Emergency admission should be the exception not the norm.

7.35 By applying these principles inappropriate admissions have been averted and lengths of stay have been reduced. Significant capacity has been released.

7.36 Much can be learned from these projects. Implementing this best practice will require joint action on the part of the whole local health community. In summary, the main lessons from all of these sources are set out in boxes 37 to 39 below:

### Box 37: Themes emerging from the Cancer Services Collaborative Improvement Partnership pilot sites on inpatient care

Services should provide:

- Better patient education about the likely symptoms, risks and complications associated with their treatment and the importance of seeking early medical advice for complications;
- More proactive management and support of patients outside the hospital, such as phoning patients on days when their white blood cell count is likely to be low and they are likely to feel particularly unwell;
- Rapid assessments of patients admitted as an emergency by an appropriate cancer specialist to avoid unnecessary admissions or to minimise the length of hospital stay;
- Preadmission assessment of patients' suitability for surgery and planning for discharge;
- Rapid systems for decision-making on the ward. Consultants should undertake daily ward rounds and make prompt decisions about the patient's care and treatment, in particular on when the patient can be discharged;
- Clear protocols agreed for cancer patients who are staying on non-cancer wards. A designated contact, who is responsible for the patient's care should be identified; and
- Good links with social care services on discharge.

### Box 38: Reducing elective breast surgery lengths of stay

- Between 1997/98 and 2005/06 the total number of surgical procedures for breast cancer (mastectomy or breast conserving operations) increased by 35%. However bed days only increased by 3% reflecting increased efficiency and shorter lengths of stay;
- However average lengths of stay remain relatively long both for mastectomy (5-6 days) and breast conserving surgery (2.8 days), with wide variations between trusts;
- Sandwell and West Birmingham Hospitals, one of the Cancer Services Collaborative pilot sites, have successfully reduced their length of stay following breast cancer surgery from six days to 23 hours; and
- This was achieved by small changes in procedure following the operation and by careful planning before and during the hospital stay to avoid delays. Both hospital staff and patients have a clear idea before the operation of when the patient is likely to be discharged.

### Box 39: Streamlining recurrent admissions of cancer patients

Sherwood Forest, one of the Cancer Services Collaborative pilot sites, has designed, tested and successfully implemented an effective Recurring Admissions Patient Alert (RAPA) system. Alerts are generated electronically when a known cancer patient is logged on the Patient Admission System (PAS). Alerts are sent as an email to a designated key worker (usually a clinical nurse specialist) via a hand held blackberry device.

The clinical team responsible for the patient is then able to assess the patient immediately. Unnecessary admissions can be avoided. When admission is needed the patient can be sent to an appropriate location.

The system has proved so successful that it is being applied across a range of tumour sites and other long term conditions. It is also now being used successfully in other hospitals.

### Next steps for inpatient care

**7.37 Given the importance of inpatient care from a patient perspective and the opportunities to release resources for other aspects of care, PCTs, working with cancer networks, should give high priority to:**

- **Reviewing current bed utilisation by both tumour group and elective/emergency split against national benchmarks;**
- **Ensuring that providers take up opportunities to participate in cancer inpatient management programmes;**
- **Developing local strategies to tackle the key causes of avoidable admissions and long lengths of stay;**
- **Considering establishing ambulatory facilities and models of care; and**
- **Using commissioning levers to drive change and get best value for money.**

**7.38 Action to improve inpatient care for cancer patients will need to involve clinicians and managers in a wide range of disciplines within the secondary sector as well as those working in the community such as GPs, community nurses and social services. PCTs are encouraged to ensure that all relevant groups and services are involved in considering and implementing these new models of cancer care.**

**7.39 To encourage and support local implementation of these recommendations, the Cancer Services Collaborative Improvement Partnership and the Cancer Action Team are developing a programme of work on inpatient management. The Inpatient Management Programme will focus initially on providing support and guidance on service improvement for different categories of patients, such as patients admitted electively for surgery or chemotherapy and patients admitted as an emergency who are subsequently diagnosed with cancer.**

7.40 Some of these recommendations will require modest investment. However, overall, they will not only result in improved experiences for patients, but also significant cost reductions. If a 25% reduction in non-surgical admissions for cancer were achieved across the country, estimates suggest this would result in a £340 million reduction in costs. Such cost reductions from improved care will clearly be very important in ensuring that the NHS can afford to deal with rising overall demand for cancer care over the coming years. Chapter 10 of this strategy sets out in more detail the opportunities for improving efficiency and minimising costs in cancer services.

### Multidisciplinary team working

7.41 Ten years ago cancer services in this country were very fragmented. There was poor communication between primary, secondary and tertiary care and within hospitals and planning



and coordination of care between specialists was often inadequate.

**7.42** Major strides were made following the Calman-Hine Report in 1995 and the NHS Cancer Plan in 2000. MDT teams are now well established as the core model for cancer service delivery within hospitals. These teams bring together all the relevant experts to plan and coordinate care.

**7.43** Depending on the cancer type these teams include surgeons, physicians, radiologists, pathologists, oncologists, clinical nurse specialists, palliative care nurse specialists, radiographers and MDT coordinators. Allied health professionals also play an important role in many MDTs, such as speech and language therapists, dieticians, occupational therapists and physiotherapists as do other professionals such as psychologists.

**7.44** Service delivery has also been enhanced by the development of cancer networks. Tumour site specific groups bring together the clinicians involved in whole pathways of care. Groups have also been established to ensure that generic services such as chemotherapy and palliative care are planned across institutional boundaries.

**7.45** However, we recognise that some services are struggling to meet the requirements set out in the NICE Improving Outcomes Guidance and in the Manual for Cancer Services. Some MDTs do not have all the relevant members or have poor attendance at MDT meetings. In addition, in some places consultants are continuing to operate on very small numbers of cases, in conflict with NICE guidance. **PCTs should not commission services from providers with such low volumes.**

**7.46** Between 2004 and 2007, peer reviews of cancer services have been carried out in each cancer network in England. Regarding MDT working, important findings requiring further action following the reviews include:

- Some lung cancer MDTs are lacking the necessary core membership of a thoracic surgeon, a radiologist, a CNS and a palliative care clinician;
- A number of breast cancer MDTs are small, treating less than 100 patients; and
- Some local upper GI teams lack CNS or palliative care support and do not have sufficient dietetic input.

**7.47** MDT working, as specified by NICE guidance, will remain the core model for cancer service delivery in the future. **Commissioners will be expected to take account of the findings from their local peer review and to decide whether all of their current MDTs are viable and can deliver the quality of care that patients should reasonably expect** (see chapter 9). In some cases, commissioners will need to ensure higher levels of attendance at MDT meetings. In other cases, it may be possible to provide an alternative, better model of service. One possibility would be for a larger and better-staffed team from a neighbouring hospital to deliver an outreach service at a hospital which cannot sustain a full service of its own. The Academy of Medical Royal Colleges' Inter-Collegiate Cancer Committee are developing professional guidelines for MDTs.

### End of life care

**7.48** Although survival rates for many cancers are improving greatly, around 125,000 people in England die from cancer every year. Many people who die from cancer receive high quality end of life care from the NHS, social care and the independent hospice sector, which meets their social, psychological, spiritual and practical needs and provides effective management of pain and other symptoms. However, too many people still do not receive this level of care. Furthermore, too often people's preferences about their care are not elicited and action is not taken to support people to live and die in the place of their choice, which for many is their home.

7.49 The government has put in place a number of initiatives to improve the provision of end of life care. This has included publication of NICE Guidance on supportive and palliative care (2004) and the funding of the NHS End of Life Care Programme (2004-07). In June 2006, the government announced that it would develop an end of life care strategy which would cover adults dying from all conditions and in all settings. The overall aims of this strategy will be to improve the quality of care for all people approaching the end of their lives and to enable more people to die in the place of their choice. A comparable strategy for end of life care in children is also in development.

**7.50 The End of Life Care Strategy is being developed in parallel with work being undertaken by SHAs on end of life care as part of the NHS Next Stage Review. It is envisaged that the End of Life Care Strategy will be published alongside the final report of the NHS Next Stage Review in Summer 2008.**

**7.51 In the interim PCTs will wish to apply the learning gained from the operating framework 2007/08 baseline reviews of end of life care services, to influence commissioning decisions in 2008/09.**

**7.52 Strategic Health Authorities will wish to ensure that emerging themes from the NHS Next Stage Review are captured and acted upon. Examples of good practice from the Department of Health funded End of Life Care Programme have recently been published (Making Change Happen). These cover developments in hospitals, the community and care homes. Interesting new evidence on the cost effectiveness of a new service model has recently been published by Marie Curie Cancer Care (see Box 40).**

#### **Box 40: Marie Curie Delivering Choice Programme**

Boston in Lincolnshire is the first place in the UK to have fully implemented the Marie Curie Delivering Choice Programme, with the NHS, Social Care and the voluntary sector all working in partnership.

A range of interventions was put in place over a three year period to deliver better end of life care for patients in their place of choice and improved support for carers.

Serving a population of 150,000, three interventions have been found to be particularly effective:

- Rapid Response Team – provides crisis and planned home care;
- Discharge Community Liaison Nurses – facilitate discharge of end of life patients from hospital and provide continuity of care between hospital and community; and
- Coordination Centre – arranges packages of home care for palliative patients through all local agencies and providers.

As a result of this innovation:

- Deaths at home have risen from 17% to 42%;
- Deaths in hospital have fallen from 63% to 45%; and
- Total costs for end of life care have decreased by 8%.

# **Part 3:**

## **Ensuring delivery and maintaining progress**



## Chapter 8: Using information to improve quality and choice

### Chapter Summary

- Better information on cancer services and outcomes will enhance patient choice, drive up service quality and underpin stronger commissioning;
- A new national survey tool to measure public awareness of risk factors and symptoms of cancer is in development. This will be used for national surveys and is likely also to be useful at a local level;
- Regular surveys of the experiences of cancer patients will be initiated, to monitor progress in this important area;
- Collection of defined datasets on all cancer patients will be mandated through the national model contract. PCTs will be responsible for ensuring that this information is collected by MDTs and sent to cancer registries;
- A new National Cancer Intelligence Network (NCIN) is being established to bring together relevant stakeholders and to act as a repository of cancer data; and
- The NCRI partners will help fund research on the population level data collated by the NCIN.

### Introduction

**8.1** Collecting and using improved information on different aspects of cancer services is central to delivering this strategy. Virtually all the improvements we expect to see over the next five years will rely on the availability of high quality, usable and relevant information. Provision of high quality information will:

- Empower patients in making important decisions about their care;
- Strengthen commissioning, as highlighted by the world class commissioning competencies;
- Enable providers to identify areas where they can make improvements;
- Facilitate greater understanding of inequalities in cancer; and

- Encourage informed national and local scrutiny of performance.

**8.2** Although there have been improvements in the information collected on cancer services, it remains patchy and the data which are available have not always been used to improve services, largely because they have not previously been brought together in a readily usable form. Addressing this is now a key priority. We particularly need to collect and use high quality data on:

- Awareness of and attitudes to cancer risk factors and symptoms among different groups within society;
- Patients' experience of treatment and care; and

- Clinical outcomes, including survival, with adjustments for co-morbidity and stage of disease.

**8.3** This chapter sets out in more detail how we will improve the data available to patients, commissioners and service providers, as well as the steps we are taking to ensure that the data we already collect is used to improve outcomes.

### Information on awareness of and attitudes to cancer

**8.4** Chapter 2 highlighted the low levels of public awareness of preventable risk factors for cancer. Chapter 3 drew attention to the link between late presentation by patients with cancer and failure to recognise that symptoms are serious or could be due to cancer.

**8.5** Robust data on levels of awareness of risk factors and symptoms is needed to highlight groups in whom awareness raising initiatives are likely to be of greatest benefit. Surveys will also be needed to monitor the impact of such initiatives.

**8.6** As discussed in chapters 2 and 3 Cancer Research UK is currently developing a cancer awareness survey tool. **Once this has been piloted, the Department of Health will initiate the first ever national survey. This is likely to be in late 2008 or 2009. The survey will then be repeated at least every two years, enabling us to track progress.**

**8.7** The awareness survey tool will also be available to use at a local level, where it will be possible to gain more detailed insights into variations in awareness and attitudes within local communities.

### Information on the experience of patients

**8.8** Chapter 5 sets out the measures we are taking to build on the progress made in improving patients' experience of their treatment and care.

**8.9** A new cancer patient experience survey tool will be developed. This will build on experience from the previous cancer patient surveys

undertaken in 2000 and 2004 and recent work to develop a specific survey tool for patients with prostate cancer. The survey tool will cover aspects of care highlighted in chapter 5 as being of great importance to patients, including the quality of:

- Face to face communication;
- Information about their condition, treatments, services, financial benefits etc; and
- Coordination of care.

**8.10 Surveys of cancer patient experience will then be undertaken annually. These will be of sufficient size to provide meaningful data on the experience of patients with specific cancers in different hospitals. It is likely that some tumour sites will be covered in one year and others in succeeding years.**

**8.11** The findings of these surveys will be made public. Individual patients may wish to take account of these findings in choosing where they wish to be treated. Local user involvement groups will also wish to use the results to focus on areas where service improvement is most needed. Commissioners and providers will wish to use the results of patient experience survey to drive up quality.

### Information on clinical outcomes

**8.12** Collecting information on clinical outcomes can in itself be a key driver for improvements in quality. For example, collection of information on service quality has been a hallmark of the NHS Breast Screening Programme. Feedback to service providers has been associated with year on year improvements in service quality.

**8.13** A considerable amount of information on individual cancer patients is already collected by cancer registries, through Hospital Episode Statistics (HES) and other national data sources. Attempts have been made to collect outcomes data through national clinical audits, but not all hospitals have submitted to these, resulting in

an incomplete picture. There are also important gaps in what is currently collected.

**Box 41: Collecting data on clinical outcomes in lung cancer**

The National Clinical Audit for lung cancer (using the LUCADA database) enables clinicians to compare their outcomes with those of colleagues in other centres and plan improvements accordingly. In 2006 around 19,000 patient records were added to the database for lung cancer patients in England. However, this represents only around two thirds of incident cases. In addition, only a minority of patients had full information recorded on staging and comorbidities.

**8.14** The most important gaps in data collection have been identified as follows:

- Information on staging and co-morbidity is only variably recorded by teams caring for cancer patients;
- Information on histopathology and cytopathology is inadequately recorded;
- For those cancers covered by national clinical audits, returns are being made for only between one third and two thirds of incident cases;
- Information on radiotherapy activity has until recently been recorded in various ways by different radiotherapy departments, with no nationally agreed dataset or data return;
- Information on chemotherapy delivery is rudimentary, largely because some providers of chemotherapy services are still using paper-based systems to prescribe and record activity; and
- Accurate information on ethnicity and other factors which may contribute to inequalities are not uniformly available.

**8.15** Much of the information required for chemotherapy and radiotherapy is already mandated through the outpatient commissioning datasets (OPCDs), but is not being well collected. To ensure that these datasets are submitted, the collection and timely onward supply of such information will be included in the national model contract.

**8.16** Primary Care Trusts (PCTs), working through their providers, need to drive up the quality of information through their contracts monitoring. Multidisciplinary teams (MDTs) will have an important role to play in collecting all the relevant items of information for all cancer patients under their care and for making this information available to cancer registries and relevant national clinical audits. By 2009 trusts should be providing registries with data in an electronic format.

**8.17** Information to be provided to registries to populate the cancer registry dataset will include:

- The Royal College of Pathologists minimum datasets;
- Information on staging and co-morbidity;
- The national radiotherapy dataset (from October 2008), which includes clinical data to enhance the OPCDS;
- Information on chemotherapy, to be defined by the National Chemotherapy Advisory Group by October 2008, for reporting from October 2009. This will include a small number of clinical items to enable MDTs and commissioners to assure themselves that prescribing is in accordance with NICE Guidance.

**8.18** Moving forward, key clinical outcome measures and cancer data collection imperatives will be reviewed on an annual basis to ensure that information remains fit for purpose.

### Coordinating information and using it to improve outcomes

8.19 The information described in this chapter will only be effective if it is collected, analysed and published in a way which is useful to patients, commissioners and service providers and other interested parties. **To co-ordinate this, a National Cancer Intelligence Network (NCIN) will be developed, building, maintaining and quality assuring a new national repository of cancer data.** Access to data will be managed through strict governance protocols which already cover cancer registries. **NCRI partners will help fund research on the data collated by the NCIN, facilitating a more informed analysis of cancer services than has ever been possible before.**

8.20 The NCIN will be tasked with ensuring optimal use is made of all bodies of data currently collected and to identify and eliminate duplication of effort. In time, this will also mean identifying and reducing the collection of data which are not being used effectively.

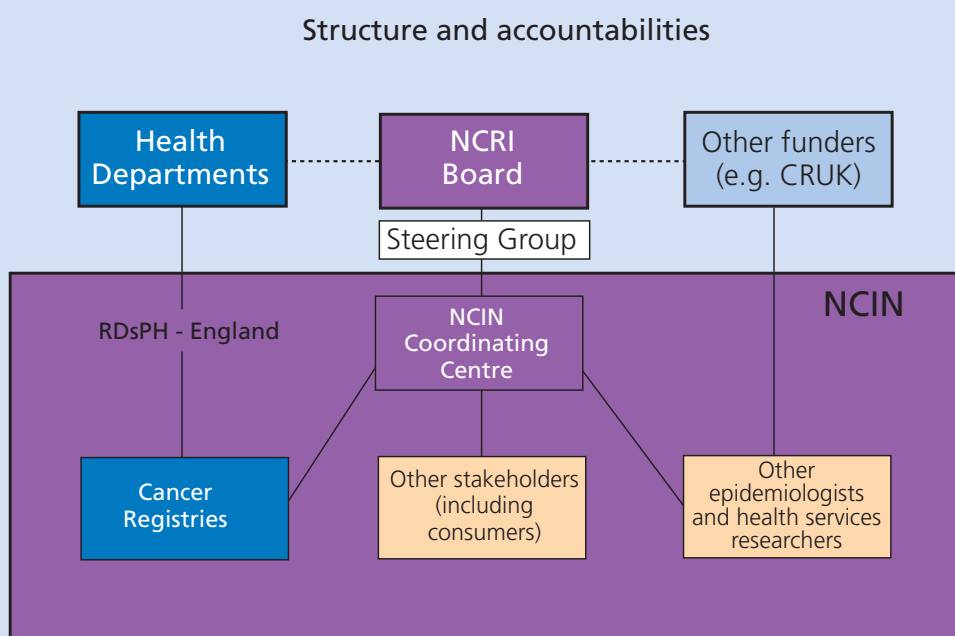
8.21 The NCIN will bring together all the relevant stakeholders in cancer information. A steering group will oversee its development, drawing on the talents and expertise of people from a wide range of disciplines.

8.22 The NCIN will manage the delivery and publication of comparative national information on diagnosis, treatment and outcomes for types of cancers and types of patient. Working with others, a new library of available information will be established and new analyses commissioned.

### Using data to improve service quality

8.23 **In partnership with the National Cancer Director, the NCIN will publish an annual report detailing the changes to clinical outcomes and patient experience across the country.** Improvements will be monitored and published as the NCIN programme matures.

Figure 14: How the National Cancer Intelligence Network will work





**Box 42: Early products expected from the National Cancer Intelligence Network**

- An electronic toolkit, bringing together information on cancer in an accessible and usable way to enable the benchmarking of services and to inform commissioning;
- Collecting and analysing information on cancers in teenage and young adults;
- Evaluating services for secondary cancers in specific tumour areas;
- Making available to the public information on clinical outcomes through NHS Choices;
- Following up the progress of patients who have been involved in clinical trials over longer periods; and
- Assessment of trends in one year survival rates for different cancers. These are a proxy for early/late diagnosis.

**8.24** As mentioned in chapter 5, we will ensure that patients will be able to access information on the experience reported by other people with similar conditions, as well as clinical outcomes data through NHS Choices ([www.nhs.uk](http://www.nhs.uk)). Written information will be available for those without internet access.

**8.25** As part of the process of incentivising service improvements, good commissioners will take data into account when making decisions about service provision and agreeing priorities for improvement with providers.

**Box 43: How commissioners could use information on clinical outcomes to improve cancer services**

If clinical outcomes data reveals that a bowel cancer provider's outcomes are lagging behind those of comparable services, then patients may choose to be treated elsewhere. Equally a commissioner could work with the provider to agree actions to improve performance. This might include better MDT working, recruiting additional staff or introducing new technologies.

**Box 44: How commissioners could use information on patient experience to improve cancer services**

If a patient experience survey reveals that the experience reported by men with prostate cancer is considerably worse than that of patients with other cancers in a particular area, then a commissioner could work with the service provider to address this disparity. Actions might include recruiting an additional clinical nurse specialist, closer working with a patient support group or introducing new decision aids to assist men when making a choice about treatment.

**Box 45: How commissioners could use information to reduce inequalities**

If data on awareness of and attitudes to cancer signs and symptoms reveals a deficit in a particular community, then commissioners can use this information to address the problems. Actions might include developing culturally-sensitive awareness and information programmes and evaluating their effect.

## Chapter 9: Stronger commissioning

### Chapter Summary

- Strong cancer commissioning will be vital to delivering world class cancer services;
- The recommendations in World Class Commissioning are directly applicable to cancer services;
- In future cancer networks will play a central role, reporting to PCTs in commissioning cancer services;
- This chapter includes a series of measures to strengthen the support available to commissioners, including publishing a cancer commissioning guide and planning toolkit; and
- Commissioners should also use existing national guidance and standards and the process of peer review to assist them in making commissioning decisions for cancer.

### Introduction

**9.1** This strategy reflects a progressive transition away from central command towards greater local control in health services. The NHS will be empowered and incentivised to drive up the quality of cancer care at a local level and to be responsive to the needs of the local population.

**9.2** Everyone with a commitment to delivering world class cancer services should have a role to play in helping deliver this strategy. However, strong commissioning will be particularly important. This chapter sets out the new support which will be available to commissioners, as well as some of the levers and tools which good commissioners will use when planning service improvements.

### Enabling strong commissioning for cancer

**9.3** Strong cancer commissioning is vital to ensuring that high quality services are delivered which reflect national priorities, the needs of local populations and offer good value for

money. Responsibility for the implementation of most of this strategy will rest with Primary Care Trust (PCT) Boards as the statutory bodies responsible for commissioning the full range of services for their population within their allocated budgets.

**9.4** To achieve the goals of this strategy, PCTs will need to work in closer partnership with other PCTs and their supporting practice based commissioning and specialised commissioning arrangements, taking strategic decisions to shape how and where care is best delivered. They will need to secure comprehensive services for cancer for their population, that are coordinated across the care pathway, including health promotion, social services, preventative and other services provided jointly with local authorities.

**9.5** In the past, commissioning for cancer services has not been as effective as it might have been. Peer Review has shown that whilst 25% of networks have demonstrated that effective collective commissioning arrangements are in place, with an agreed three year strategic

framework for planning future cancer services and clearly identified priorities, a further 25% were found to be struggling in all these areas. This, therefore, remains an important area for development.

9.6 It is important to recognise that commissioning for cancer is particularly complex. There are many different types of cancer, each with a different care pathway involving clinical teams in the community, in acute general hospitals and in specialist centres. Some aspects of the diagnosis and treatment of cancer are rare and require highly specialised commissioning at a national or Strategic Health Authority (SHA) level. Other aspects of cancer are common and overlap with non-cancer services (such as endoscopy, imaging, pathology and some surgery) and thus should be commissioned at a more local level.

9.7 A significant amount of cancer care is best commissioned at populations of one to two million people because of the critical mass required to provide effective care. This includes radiotherapy, specialist surgical services for upper gastrointestinal, urological, gynaecological and head and neck cancers and aspects of chemotherapy. For this reason we continue to recommend that cancer commissioning is coordinated across a network of care, based on patient care pathways into these services, rather than formal organisational boundaries.

9.8 The Department of Health has published *World Class Commissioning*, which sets out how PCTs should ensure strong commissioning across all health services. A support and development framework will be available in 2008 to help PCTs gain the capability to become world class. The Cancer Reform Strategy sets out specific support that will be available to cancer commissioners.

**9.9 To strengthen commissioning of cancer services the following actions are already being taken:**

- **A guide for cancer commissioners, is currently in development, this will set out the appropriate level for the commissioning of different cancer services;**

- **As mentioned in chapter 8, an electronic commissioning toolkit, is being developed to provide SHAs, Specialist Commissioning Groups (SCGs), cancer networks, PCTs and NHS Trusts with comparative data on incidence, survival and mortality from cancer and on information available from national sources such as hospital episode statistics. The Cancer Action Team will support networks in using this toolkit and will commission upgrades as and when is necessary; and**
- **Service specifications for each cancer pathway are being developed, which will be linked to the Map of Medicine, a process which offers high quality clinical information, linked to the NHS IT Programme.**

9.10 Given the cross-organisational way in which many cancer services are delivered, collaboration should be an important part of cancer commissioning:

- Patients, local voluntary service providers, alternative providers and other stakeholders should be involved in influencing the way in which services develop;
- Commissioners and providers should work together to improve service quality and safety and plan future provision;
- Clinicians and managers should collectively drive forward innovation in the way services are delivered; and
- PCTs should work together to develop strategies and agree priorities.

9.11 Cancer networks play an essential role in fostering this collaboration. PCTs in some networks have been very successful at bringing together the relevant commissioning partnerships to plan and monitor service delivery. Other networks have lacked PCT engagement and network teams have largely worked with providers in isolation of mainstream health economy systems.

9.12 Cancer networks play an essential role in fostering this collaboration. PCTs in some networks have been very successful at bringing together the relevant commissioning partnerships to plan and monitor service delivery. Cancer networks have been less successful where they have lacked PCT engagement, network teams largely working with providers in isolation of mainstream health economy systems.

**9.13 We believe that cancer networks should play an important part in delivering the actions set out in this strategy. However, now is the appropriate time to review their role. During the development of this strategy the advice we have received and which we endorse is that:**

- **Networks teams should act as agents for commissioners, supporting them to coordinate their activities and providing shared expertise, maintaining the dialogue with clinical teams and users, agreeing clinical guidelines and pathways and driving forward innovative, high quality care;**
- **Networks will typically operate at 1½ – 2½ million population and usually cover five or six PCTs, as this corresponds to patient flows across a care pathway;**
- **For less common cancers, networks should work with each other to develop strategies and plans working with their specialised commissioning groups;**
- **Networks will act as advisors to PCTs on issues such as: needs assessment and demand profiling, prioritisation within the cancer agenda, service improvement and redesign, quality assurance and peer review, pathway and provider performance, patient experience and value for money;**
- **Networks should ensure contestability of services between providers as well as co-operative working;**

- **Networks should respect and support any patient who chooses to receive treatment at National Institute for Health and Clinical Excellence (NICE) compliant services outside the network;**

- **Network teams will need to develop stronger links with leads for cancer in Professional Executive Committees and locality practice based commissioning arrangements;**

- **There should be sound hosting arrangements for network teams and strong leadership from a designated PCT CEO, ensuring that networks are accountable to commissioners as well as with PCT contract leads; and**

- **Core funding for network teams and user and clinician engagement mechanisms should be from commissioners, although additional funding can also be sought from other sources.**

9.14 Fulfilling this function will require experienced clinical and managerial leadership, with networks needing to draw on expertise relating to public health, finance and pharmaceuticals. Further detail about the future role of networks will be included in the commissioning guide for cancer.

9.15 As part of their performance management role, SHAs will be expected to:

- **Monitor the performance of PCTs and SCGs in relation to cancer commissioning, against the key criteria set out in this strategy and the commissioning guide;**
- **Ensure that effective collective commissioning arrangements are in place that are integrated into mainstream health economy needs assessment, contracting and performance systems, supported by clearly defined working arrangements between commissioning partners; and**

- **Assess whether PCTs, through cancer networks, have appropriate mechanisms in place to ensure user involvement in commissioning.**

**9.16** Commissioners should ensure that the views and expertise of all potential providers are included within cancer networks. The lead PCT for each cancer network will want to ensure that the principles for market entry, which have

been developed by the Department of Health to help guide commissioners, are used appropriately. All providers of cancer services will be expected to participate in the developing and monitoring of agreed network guidelines and facilitate clinical engagement in this.

**9.17** The overall responsibilities of PCTs in relation to cancer commissioning are summarised below:

#### **Box 46: Competencies for World Class Commissioning: Application to Cancer Services**

1. The PCT engages with and understands the views and priorities of local NHS organisations and is respected as the local leader of the NHS.
  - PCTs working collectively through networks will engage with all organisations contributing to cancer care pathways.
2. The PCT works collaboratively with partners.
  - For cancer it is essential that clusters of PCTs across a network work effectively together, as care pathways frequently cross boundaries.
  - Partnership with Local Authorities is also vital.
3. The PCT leads and seeks continuous and meaningful engagement with people patients and communities to shape services and improve health.
  - Network partnership groups can facilitate this.
4. The PCT leads continuous and meaningful engagement of all clinicians to inform strategy and drive quality, service design and resource utilisation.
  - Network clinical groups can facilitate this.
5. The PCT undertakes robust and regular needs assessments that establish a full understanding of current and future local health needs and requirements.
  - The network executive team can provide crucial information to assist the PCT in doing this.
6. The PCT prioritises investment according to local needs, service requirements and the values of the NHS.
  - Cancer networks can make recommendations on prioritisation.
7. The PCT influences provision to meet demand and secure required clinical and health and wellbeing outcomes.
  - The network can engage with providers on behalf of the PCTs.
8. The PCT promotes and specifies continuous improvements in quality and outcomes through clinical and provider innovation and configuration.
  - The cancer network can promote service innovation and redesign.
9. The PCT deploys procurement skills that ensure robust and viable contracts.
  - Procurement remains a key responsibility of individual PCTs.
10. The PCT performance manages providers to ensure contract compliance and continuous improvement in quality and outcomes.
  - The network can act on behalf of and advise the individual PCTs where appropriate while ultimate responsibility lies with individual PCTs.
11. The PCT demonstrates excellent financial management.
  - Networks can help to identify opportunities for managing budgets more effectively.

#### Box 47: World class commissioning for cancer: PCT responsibilities

PCTs also have a number of cancer-specific commissioning responsibilities, including ensuring progress on:

- Using resources effectively and efficiently, especially in relation to inpatient care;
- Collecting and reporting public awareness and patient experience surveys and agreed clinical datasets;
- Increasing public awareness of factors associated with cancer and symptoms of the disease and promoting earlier presentation by patients with symptoms;
- Providing screening programmes in line with national guidance and with high levels of coverage;
- Reducing inappropriate delays in investigation and onward referral of new cancer patients by GPs;
- Achieving waiting time standards;
- Enabling all patients to receive care from a properly constituted multidisciplinary team, with complex surgery only being undertaken by centres which are compliant with NICE guidance;
- Providing information and support to promote informed choice in treatment and care;
- Delivering safe and effective radiotherapy in accordance with the recommendations of the National Radiotherapy Advisory Group;
- Ensuring the availability of safe and effective chemotherapy with new treatments being delivered in accordance with NICE guidance and having robust and fair processes in place for making decisions on drugs that have not yet been appraised by NICE;
- Providing high quality supportive and palliative care in line with NICE guidance.

PCTs can be assisted with almost all of these responsibilities by their cancer network.

**9.18** With cancer incidence increasing, significant increases in capacity will be required, although this may be in different forms of service than already exist. Commissioners should encourage innovative methods of delivering this additional capacity.

### User involvement

**9.19** Effective user involvement should have a central role to play in improving the quality of patient care and delivering a patient-centred NHS. User involvement in cancer services is relatively well developed in England through network partnership groups and other user involvement channels. The creation of new Local Involvement Networks (LINKs) to better support the views of the local community and reflect patient experience represents an important opportunity to build on this.

**9.20** Good commissioners will want to ensure that they have appropriate user involvement when making decisions about service provision. As part of this they should consider how best to assist LINKs in engaging with current user involvement structures in cancer networks (such as partnership forums and user involvement facilitators). Consideration should also be given to ways of facilitating user involvement from those who do not join groups or attend meetings but have valuable experience of services. This could be done by mail, phone or e-mail, with professional support for those with specific needs (eg learning disabilities).

**9.21 The Cancer Action Team will continue to work with commissioners, through cancer networks, to identify and spread good practice in relation to user involvement.**

## National guidance and standards

9.22 National guidance will continue to play a vital role as cancer services develop over the next five years. Much of this guidance has been developed by the NICE and predecessor bodies.

9.23 NICE's most high profile guidance on cancer relates to the use of new technologies (see chapter 4). However, there are several other forms of guidance which it will be important for commissioners to take into account.

9.24 **Improving Outcomes Guidance (IOG)** on cancer services now covers the vast majority of all cancers. Implementation of this guidance, which involves the establishment of multidisciplinary teams and reconfiguration of some complex services is now well advanced for many cancers and is scheduled to be complete for less common cancers by 2010 (see chapter 4).

9.25 The Healthcare Commission and in future the Care Quality Commission will play an important role in assessing whether cancer services deliver against these standards.

**We will consider asking the Care Quality Commission to undertake an improvement review of cancer in 2009 to assess progress on implementing the IOGs. The regulator will also be encouraged to take action against Trusts which continue to undertake work for which they are not designated by their SCG. We will also include IOG implementation in the national model contract meaning that only fully IOG compliant services should receive full payment.**

9.26 Clinical guidelines have been developed or are under development by NICE for several of

the most common types of cancer. These guidelines provide advice to commissioners and providers on the appropriate diagnosis, treatment and care for patients with particular conditions. They are developmental, reflecting the fact that they cannot be delivered in their entirety overnight but are something that the NHS should be working towards delivering. No national targets have therefore been set for implementation although progress towards implementation is expected.

**9.27 In future we will monitor the implementation of existing guidelines through the improved data on clinical outcomes and results will be made available to the regulator. A key criterion for future guideline development will be whether evidence suggests there is substantial variation in clinical practice or where practice is changing rapidly.**

## Peer review

9.28 The National Cancer Peer Review Programme, which is led by the Cancer Action Team and includes expert clinical and user representation, provides important information about the quality of cancer services across the country. Between 2004 and 2007 Peer Reviews of cancer services were carried out in each cancer network in England. The results show clear links between strong network leadership, representative and effective network board activity, robust and clear commissioning arrangements and overall progress on cancer.

9.29 There are some examples of excellent progress in implementing IOGs, but there are also instances where commissioners and providers face the challenge of both agreeing compliant IOG Action Plans and translating

### Box 48: Summary of NICE products to help cancer commissioners

- Improving Outcomes Guidance on twelve cancer types or groups of cancer, together with general guidance on supportive and palliative care;
- Three clinical guidelines, with six in development;
- 29 technology appraisals, with eleven in development; and
- 40 interventional procedure guidelines.

those plans into the reality of clinical services on the ground. Three year planning was found to be weak in more than half of networks. Further work is required to ensure that effective collective commissioning arrangements are in place in all networks.

**9.30** Full information on the compliance of individual teams and services with the peer review measures is available to commissioners and providers on the CQUINS website. Work is ongoing to make this website more accessible and user-friendly.

**9.31** An independent evaluation of the cancer peer review programme has demonstrated strong support for the programme to continue, but has also indicated that the programme should be modified. At present peer review focuses largely on measures of structure and process. Over time, as reliable measures of outcome become available, there should be a shift in emphasis. In addition we have listened to the concerns of reviewers and those being reviewed about the burden of inspection.

**To reduce this, the peer review programme will focus more on annual self assessment. Self-assessments made by individual teams and services will need to be signed off by the relevant provider CEO and by the cancer network. Some external visits will continue, but this will become the exception rather than the rule once a team has demonstrated a high level of compliance with the measures. Peer review data will continue to be published to assist commissioners and promote transparency on service performance.**

### Ensuring that tariffs support service improvements

**9.32** The funding mechanism for cancer services should recognise and incentivise appropriate and effective care. At present, there is some evidence that the Payment by Results (PbR) tariffs are not always achieving this objective. For example:

- Some complex cancer surgery currently falls under the same Healthcare Resource Group (HRG) as less complex non-cancer procedures. As the tariff price for that HRG is based on the average costs of all procedures within that HRG, the complex cancer work will therefore be under rewarded and there will be no incentive for trusts to specialise in doing this activity;
- There will be no motivation for acute trusts to cease providing simple care and focus on more complex cases if the tariff is not adjusted to reflect a more difficult and cost intensive case mix in secondary care;
- There is a lack of clarity as to how MDT planning meetings are reimbursed; and
- The tariff is meant to cover capital costs, however it cannot take account of the high variation in the cost of installing new bunkers for radiotherapy.

**9.33** To ensure that tariffs appropriately incentivise good practice and do not penalise innovation, we commissioned a review of cancer tariffs. The review looked at both how cancer is treated under the current HRGs (HRGv3.5), which will be used for payment in 2008/09 and the next version of HRGs, HRG4, which will establish new national currencies for radiotherapy, chemotherapy and specialist palliative care. This review identified the following key issues as particular priorities if PbR is to effectively support cancer services:

- Improving coding quality and consistency;
- Ensuring fair payment for MDTs;
- Ensuring that the HRG4 structure works for funding chemotherapy;
- Improving funding of outpatient cancer care;
- Ensuring fair payment for the highly complex cancer procedures; and
- Supporting investment in new technology and capital such as radiotherapy bunkers.



9.34 As a result the Department of Health will:

- Improve high level guidance, including the need for robust costing of MDTs to help commissioning;
- Make use of expert panels for cancer services to ensure HRG4 is fit for purpose;
- Investigate the feasibility of normative adjustments to cancer tariffs, or a separate or a separate outpatient tariff for cancer in key specialties. This may help both with the problems of reimbursing complex cancer surgery and recognising the need for Multidisciplinary Assessments as part of a first outpatient appointment; and
- Keep the relationship between capital expenditure and the tariff under review.

## Chapter 10: Funding world class cancer care

### Chapter Summary

- Cancer programme costs are at least £4.35 billion a year, most of which is spent on hospital services;
- We spend less than comparable countries and will need to continue to invest in cancer;
- Cancer spend varies across the country but cost effectiveness and outcomes are key;
- Incidence and drug costs will continue to rise and investment will follow; and
- There are significant opportunities to save money and deliver better outcomes, freeing up resources for reinvestment in cancer care. In particular, inpatient costs offer significant opportunities for saving.

### Introduction

**10.1** When the NHS Cancer Plan was launched in 2000, the government committed an extra £570 million to meet the cost of extra staff and equipment. In fact, additional spending on cancer came to £693 million over a three year period. The cancer workforce has expanded considerably, with around 49% more consultants specialising in cancer in 2006 than in 1997<sup>50</sup>. Major investments have also been made in equipment such as CT scanners, MRI scanners, linear accelerators, breast screening equipment and also in the use of new drugs.

**10.2** As the incidence of cancer increases and our ability to treat the disease improves still further, so there will be additional cost pressures on cancer services. Significant further investment in cancer will be necessary to meet the challenge of cancer and to deliver world class services for all those affected by it.

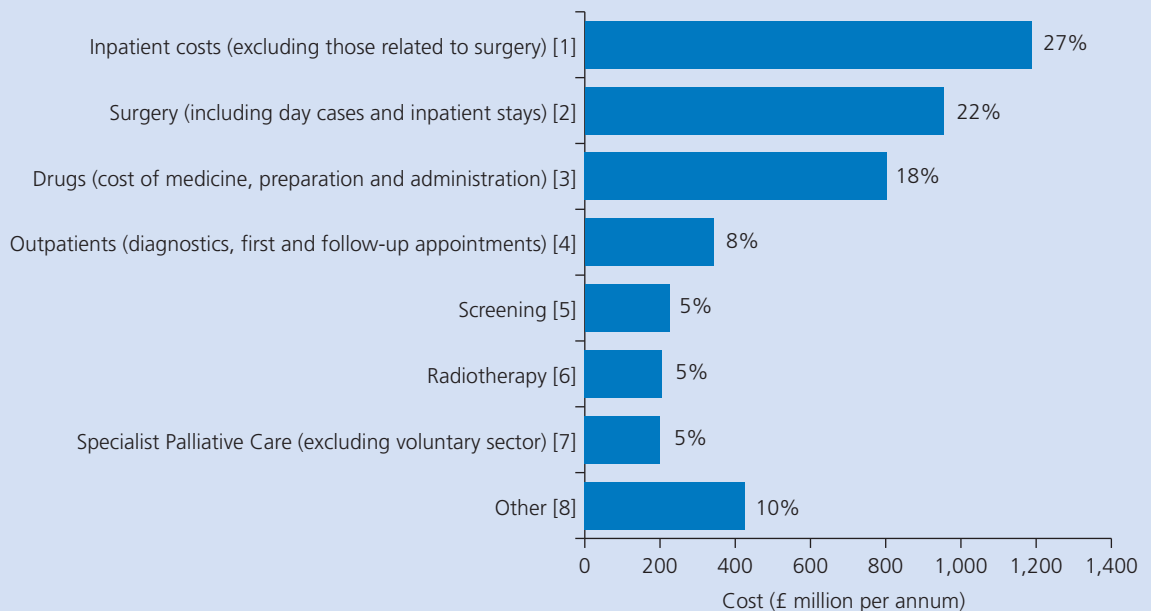
**10.3** There is also scope to make more effective use of existing resources. To deliver good value for money and to make the investments which will be important to deliver world class cancer

services, it is vital that we maximise the effectiveness of our current spending. Doing so does not need to be at the expense of quality. There is good evidence that streamlined, less expensive services can deliver better outcomes. The guiding principle should be to get the greatest benefit to patients for the money invested.

**10.4** This chapter analyses current spending on cancer services and sets out how the initiatives announced in the Cancer Reform Strategy will be paid for. It also flags up some of the factors that good commissioners will want to consider when making decisions about future expenditure on cancer.

### Current expenditure on cancer in England

**10.5** English cancer spend has increased by 27% over the last three years and cancer is now the third largest disease programme in the NHS, behind mental health and circulatory diseases, costing the NHS around £4.35 billion a year. Approximately 80% of this is spent in the acute

**Figure 15: Estimated total NHS spend on cancer care<sup>1</sup>**

[1] Source: Hospital Episode Statistics 2005/06 combined with NHS Reference Costs 2005/06. Includes critical care beds and excess beddays

[2] Source: Hospital Episode Statistics 2005/06 combined with NHS Reference Costs 2005/06. Includes critical care beds and excess beddays

[3] Source: Prescription Cost Analysis 2005/06 ([www.ic.nhs.uk](http://www.ic.nhs.uk)) plus Hospital Episode Statistics 2005/06 combined with NHS Reference Costs 2005/06 where HRG code is chemotherapy. Note this excludes other drugs provided in secondary care (which are included in the inpatient costs).

[4] Source: NHS Reference Costs 2005/06. Included cancer specific specialties; common diagnostic tests for cancer; and assumed one new and one follow up appointment per surgical inpatient.

[5] Source: NHS Cancer Screening Programmes

[6] Source: NHS Reference Costs 2005/06

[7] Source: National Council for Palliative care suggested cancer accounts for 90% of £211-233m NHS palliative care funding

[8] "Other" includes: GP visits (Source: Activity from RCGP survey 2003. Unit costs from PSSRU ([www.pssru.ac.uk](http://www.pssru.ac.uk))), Bone Marrow Transplants (Source: NHS Reference Costs 2005/06), A&E attendances and Observation (assumed 11% of A&E costs are cancer related, equal to the proportion of all emergency admissions that are cancer related. Source: NHS Reference Costs), and a proportion of the overall NHS costs for the following: Paramedic services, Direct Access tests, Community Nursing, Community Therapy, Rehabilitation, Paramedic services (Source: NHS Reference Costs 2005/06. Assumed cancer accounts for 3-6% of each category).

\*These figures are in 2005/06 prices.

sector (including outpatients, diagnostics, treatment and emergency care) and the remaining 20% is spent in the community including screening programmes, GP consultations and palliative care.

**10.6** However, this estimate does not include several key elements of cancer services, including:

- Preventative services such as smoking cessation, which contribute to better health outcomes across a range of diseases;
- Assessment, diagnostics and support prior to diagnosis, including for those patients where cancer is excluded. Pre-diagnosis assessment and diagnostics represent a significant additional cost to the NHS. For example, a recent modelling exercise commissioned by the Department of Health suggested that the cost of investigating potential bowel cancer amounts to one quarter of the total cost of £1 billion expenditure on the condition; and

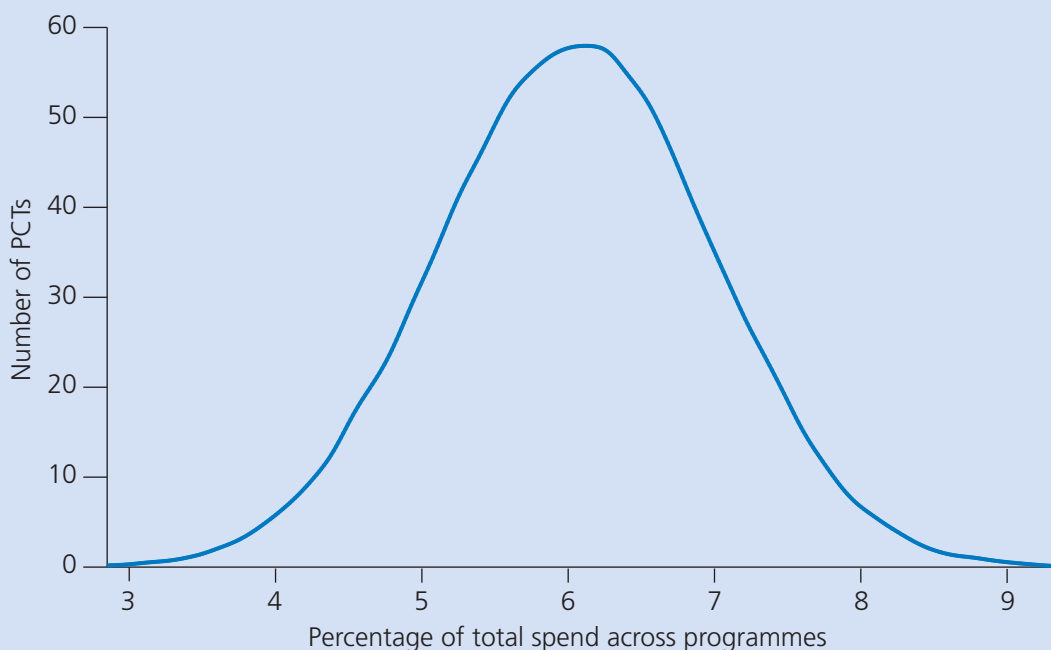
- Palliative care provided by the voluntary sector, which is estimated to cost in excess of £200 million every year.

### Variations in spend on cancer in England

**10.7** Different areas of the country may have different health needs and it will be important for Primary Care Trusts (PCTs) to take this into account when making spending decisions. However a Kings Fund analysis of programme budgeting data from 2003 to 2005 found that some PCTs spend much more on cancer than others, even after differences in the health needs of local populations and other factors have been taken into account. The latest Programme Budgeting data from 2006/07 shows there is still wide variation in the proportion of PCT's overall spend that goes on cancer, ranging from 3.6% to 9.1%.

**10.8** There is also significant variation in expenditure on National Institute for Health and Clinical Excellence cancer drugs by cancer network.

**Figure 16: Spending on cancer in 2006/07 as percentage total of PCT programme spend**



**10.9** Some variation in PCT spending may be explained by factors such as incidence, length of hospital stay and emergency admissions. However, these factors are unlikely to be the full story. Good PCTs will wish to benchmark their expenditure on cancer services with that of other PCTs with similar health needs. They should use the resources published alongside this strategy and the improved information on outcomes which will be generated by the actions we are taking, to critically appraise whether they are spending appropriate levels on cancer services in order to appropriately meet the needs of their local population.

### Comparison of spend with other countries

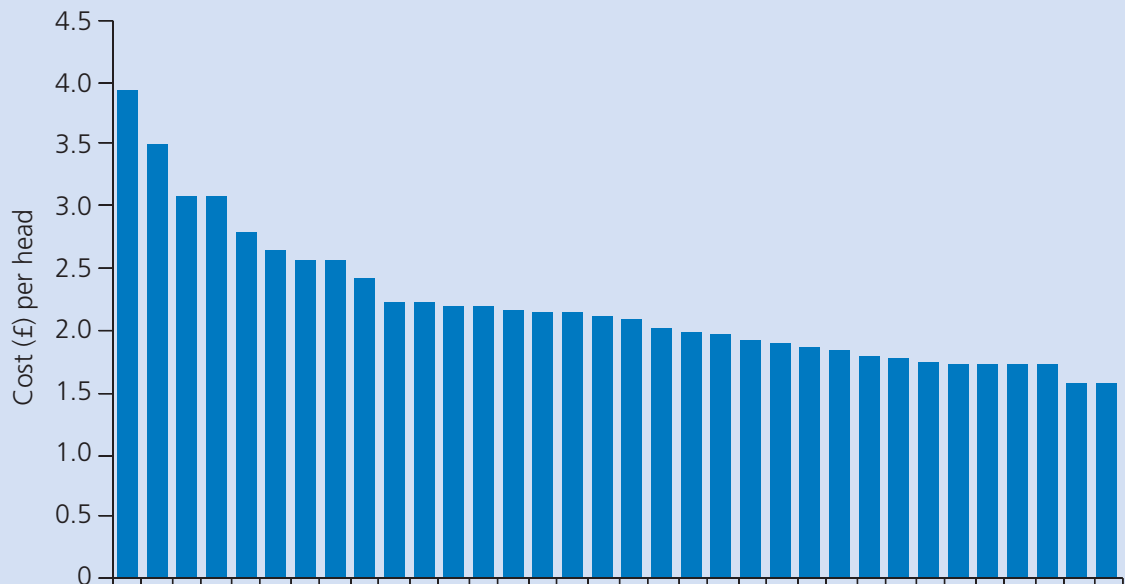
**10.10** Record investment in the NHS since 2000 has been mirrored by substantial increases in the funding for cancer services. However, this follows a prolonged period of low investment

in health services compared to the rest of Europe and significant amounts of this investment have been dedicated to addressing this historic shortfall.

**10.11** Spending per capita on cancer services remains low compared to some other European countries. Spending on cancer in England is £80 per capita, compared to £121 per capita in France and £143 per capita in Germany. Overall, England spends 5.6% of its public healthcare budget on cancer, compared to 7.7% in France, 9.2% in the United States and 9.6% in Germany.<sup>51</sup>

**10.12** There is no consensus on the correct level a country should spend on cancer services. This strategy marks a shift towards assessing the performance of cancer services using measures of outcomes and outputs rather than simply inputs. However if outcomes fall below the aspirations set out in this strategy then it will be

**Figure 17: Estimated cost per head of NICE-approved cancer drugs used in hospitals in Jan-Jun 2005, by cancer network**



Method: Calculations based on volumes dispensed (from IMS-Health) and on lowest list prices for each NICE-approved cancer drug.

important to review the reasons, including funding. **The government will therefore continue to monitor how spending on English cancer services compares to the spending of other countries, as well as variations in spending on cancer within England.**

### Meeting future cost pressures

10.13 Cancer costs are increasing in all developed countries due to increased incidence, advances in all forms of treatment and the impact of survivorship.

10.14 The estimated 1.5% yearly increase in incidence in England means that the baseline costs of treating cancer would increase by at least a similar percentage, adding £70 million to overall costs each year.

10.15 Drug costs have also recently been growing at over £100 million per year. During the development of this strategy industry and clinicians told us that they estimate a future growth in spending on drugs of approximately £60-80 million per annum. Reasons for this upward trend include:

- Greater use of adjuvant treatments, especially in common cancers;
- More treatment options in advanced disease;
- New forms of drugs, which are given in addition to chemotherapy; and
- Increasing rate of introduction of new drugs.

**10.16 Subject to cost effectiveness being demonstrated, these cost pressures will be met through increased allocations to the NHS, enabling commissioners to rise to the challenge of ensuring world class cancer services for the communities they serve.**

10.17 As well as the cost pressures listed above, this strategy includes a number of measures to improve the quality of cancer services which will have costs, with additional investment totalling some £680 million.

10.18 **Major capital investments related to the commitments made in this strategy include digital mammography machines and increased radiotherapy capacity to achieve the recommendations set out in the National Radiotherapy Advisory Group report.**

10.19 **Major additional revenue cost drivers related to the strategy include:**

- **Improving awareness and earlier presentation;**
- **Expanding the breast screening programme;**
- **Expanding the bowel screening programme;**
- **Reducing cancer waits;**
- **Increasing radiotherapy capacity (eg workforce);**
- **New service models to replace inpatient care;**
- **Enhancing care of survivors;**
- **Collecting better data on cancer to support world class commissioning; and**
- **Delivering new training initiatives.**

10.20 **However, this strategy also sets out how many of these costs can be offset over time by improving the use of existing resources. Major savings will include:**

- **Reducing admissions and length of stay for non-surgical cancer patients;**
- **Reducing elective stays for surgery;**
- **Improving efficiency of follow up after treatment; and**
- **Improving efficiency of cervical screening.**

**10.21** Further details of these costings are included in the Impact Assessment published alongside this document.

**10.22** By far the greatest scope for improved efficiency relates to inpatient care, which is the largest area of cancer spend. Chapter 7 sets out how this can be achieved, freeing up resources and improving the quality of care that patients receive. These efficiency savings will free resources to ensure that NHS treatment services keep pace with rising incidence of cancer in coming years.

**10.23** Further details on the estimates of costs and savings can be found in the Impact Assessment, published alongside this strategy.

### Focusing spending on cost effective interventions

**10.24** It is important that cancer spending is focused on cost effective services. Future cost pressures can also be mitigated by reallocation towards more cost effective interventions or increasing the productivity of existing ones.

**10.25** Prevention remains the best form of tackling cancer, reducing the human suffering caused by the disease and improving outcomes. There is also a strong economic case for investing more in prevention, therefore reducing the pressure on services in the long term. Chapter 2 sets out the measures we are taking to improve the prevention of cancer.

**10.26** However, many people will unfortunately continue to develop cancer and will require a variety of forms of treatment for different stages of disease. Commissioners will therefore need to invest in a variety of interventions across the care pathway, ranging from prevention to end of life care.

**10.27** Where possible, the same methodology for assessing the impact of services should be applied across the care pathway. Measuring cost effectiveness allows us to assess the difference in patient outcomes that different interventions deliver. Cost effectiveness is usually measured as “costs per life year”, showing the cost of a treatment divided by the additional years it adds to a patient’s life, or “cost per quality adjusted life year”, which also takes into account any impairment or improvement in quality of life the treatment will cause.

**10.28** A recent study by the University of York’s Centre for Health Economics<sup>52</sup> has used Department of Health Programme Budgeting data to generate estimates of the overall link between health expenditure and health outcomes in two of the largest health care programmes (cancer and circulatory diseases) between 2002 and 2004. This suggests that the mix of interventions offered by English NHS cancer services compare favourably with the criteria used by NICE to assess cost-effectiveness.

**10.29** Good commissioners will want to continue to assess the cost effectiveness of all cancer interventions when making decisions on future spending. Where possible, they should use sources of national guidance, such as NICE, when doing so.

## Chapter 11: Building for the future

### Chapter Summary

- The cancer environment continues to change rapidly. Delivering world class cancer services will require effective planning;
- The NHS will need a skilled and flexible workforce, appropriate cancer facilities, good horizon scanning, high quality research and clear national leadership if it is to meet the cancer challenges of the future;
- The National Cancer Director will deliver annual reports on progress as this strategy is delivered; and
- We will also work with other countries to compare progress, share ideas and spread good practice.

### Introduction

11.1 Cancer services have changed dramatically over the last ten years and the indications are that they will continue to do so over the next decade:

- The number of new cases of cancer is set to continue to rise, largely reflecting demographic changes within society;
- More people will survive cancer or live for long periods on active treatment; and
- Our knowledge of how to prevent, diagnose and treat cancer will continue to expand.

11.2 Given the changing cancer environment, we will need to continue to reassess the progress made in tackling cancer and refine our approach to reflect new developments. There will, however, be several prerequisites to delivering world class cancer services:

- A skilled and flexible workforce;

- Appropriate facilities;
- Good horizon-scanning;
- High quality cancer research; and
- Clear national leadership, support and oversight.

### A skilled and flexible workforce

11.3 The cancer workforce is extremely diverse and will remain so:

- A relatively small number of clinicians dedicate the whole of their working time to cancer (such as medical oncologists, clinical oncologists, haemato-oncologists, specialist cancer nurses and those working on oncology wards);



- A much larger number of clinicians dedicate a significant part of their working time to cancer (such as many pathologists, radiologists, allied health professionals, general and community nurses, surgeons, physicians, haematologists and anaesthetists);
- Dealing with cancer patients represents only a relatively small part of the workload of GPs. However, they spend much of their time caring for patients who have symptoms that might possibly be due to cancer; and
- Outside the NHS many staff, such as social workers or carers, play an important role in supporting cancer patients.

**11.4** As set out in chapter 1, the number of specialists working in cancer related specialties has increased markedly over the past decade and is set to increase further over the next five years. This has been supplemented by significant changes in the roles undertaken by non-medically qualified staff. Indeed, without these changes many of the improvements in services would not have been possible:

- The introduction of the four tier model for diagnostic radiographers has been introduced with great success in some areas, for example enabling the breast screening programme to be successfully extended to women up to the age of 70 years;
- The 4 tier model has also been introduced in some radiotherapy departments, though there is potential for wider uptake of this approach; and
- Nurses have been trained to undertake endoscopy (gastroscopy, flexible sigmoidoscopy and colonoscopy). This has helped to reduce waiting times for endoscopy services and facilitated the roll out of the NHS Bowel Cancer Screening Programme.

## Workforce development

**11.5** A key function for each Strategic Health Authority (SHA) is organisational and workforce development, including the development of strategic regional workforce plans, based on supply forecasts and local delivery plans. However the Cancer Policy Team and the Cancer Action Team should continue to assist the SHAs in this function, ensuring consistency across the cancer workforce. Developments in new treatments and care settings will require changes to the workforce and the cancer teams are best placed to advise SHAs on the impact these may have and provide further detailed information on cancer workforce profiles. Recent examples of this support include:

- Working with Skills for Health to develop skills competences for professionals aligned to patient pathways to inform localised skill mix and training needs assessments;
- Identifying competence frameworks for the development of new and extended roles within cancer services, for example Clinical Nurse Specialists and the Integrated Cancer Care Pathway Care Tracker role; and
- Supporting and developing multidisciplinary teams (MDTs) by identifying and sharing the key factors for the successful working of MDTs.

**11.6** SHAs will also want to consider how best to make links with those responsible for workforce development outside the NHS such as Skills for Care, which is responsible for developing the skills and qualifications of the adult social care sector.

## Training

**11.7 In general, workforce development and the commissioning of training programmes is the responsibility of SHAs and PCTs and should take account of local needs and circumstances. However, where it makes sense to identify and commission training pilots at a national level, the Cancer Policy Team and Cancer Action Team will continue to do so. This work will be undertaken in partnership with SHAs.**

**11.8** Service improvements have only been possible because of the hard work and dedication of the staff who work with cancer patients. It is vital that they are supported with appropriate training. Several training initiatives relating to the continuing professional development of senior clinicians have been initiated centrally over the past few years to fulfil commitments in the NHS Cancer Plan or to respond to new developments. These training programmes are helping to drive up the quality of care and to reduce waiting times for patients with cancer. Programmes include:

- A national endoscopy initiative which aims to improve the quality and quantity of endoscopists;
- A national training programme for all 187 colorectal cancer teams in England, with a central focus on improving the quality and uptake of total mesorectal excision (TME);
- Advanced communication skills training; and
- Sentinel node biopsy training for breast cancer teams, reducing the need for patients to stay overnight in the hospital, lower costs to the NHS, enabling faster recuperation and resulting in higher patient satisfaction.

**11.9** The “Making Progress on Prostate Cancer” report announced plans to develop master classes in specialised urological surgical techniques to improve outcomes of surgical procedures in the treatment of prostate cancer. Following advice from the Prostate Cancer Advisory Group, it was decided that the focus should extend to cover MDTs rather than just surgeons. In March 2007 St James Hospital NHS Trust, Leeds was awarded the contract to run a small pilot of three to four training courses involving a total of 15-20 MDTs, an evaluation will be completed within twelve months of work commencing. The aim of the pilot is to enhance MDT working and improve the quality of surgical techniques (focusing initially on open prostatectomy) to improve clinical outcomes, reduce side effects and shorten hospital stays.

**11.10** A pilot training programme will be launched for laparoscopic surgery in colorectal cancer (see chapter 4), following National Institute for Health and Clinical Excellence guidance recommending this approach. The aim is to improve outcomes and experience for patients and potentially save the NHS money for reinvestment. Contracts to run the training centre as part of the pilot are to be awarded by January 2008 and an evaluation of the pilot will be produced 18 months later. Depending on the results and evaluation of the pilot, consideration will be given to the possibility of rolling out the training programme to other centres or other procedures.

**11.11** Training for radiographers will be improved through the provision of virtual environments for radiotherapy (VERT) in radiographer training schools and in radiotherapy centres (see chapter 4). The objective of introducing this training is to reduce the current drop out rate from radiotherapy training (35%) and reduce the pressure on clinical departments, thereby increasing capacity. By installing VERT in as many sites as possible during 2007/08 clinical training capacity will be increased and pressure reduced on service departments whilst providing learning for students in a “safe” environment. VERT can be potentially provided at the ten radiotherapy educational providers and the 50 clinical sites from 2007/08 (subject to meeting applicant criteria).

### Appropriate facilities

**11.12** Since the publication of the NHS Cancer Plan unprecedented new and replacement CT & MRI scanners, linear accelerators (linacs) and other essential equipment for the diagnosis and treatment of cancer have been made available to the NHS through central programmes. By October 2007, 158 new MRI scanners, 167 linacs, 247 CT scanners and over 730 items of breast screening equipment had been delivered. This means that, in total, approximately 83% of MRI scanners, 85% of CT scanners and 81% of linacs, now in use in the NHS, were installed since January 2000.<sup>53</sup>

**11.13** Between 1999/2000 and 2005/06 the number of CT scans undertaken each year on NHS patients has increased by 83% (from 1.36 million to 2.48 million). MRI activity has increased by 99% (from under 600,000 to over 1.1 million). The latest monthly figures from the national diagnostic data collection, part of the 18 week pathway monitoring, shows the median wait for an MRI scan was four weeks and the median wait for a CT scan was two weeks in September 2007.

**11.14** Despite this progress, England is still below the international average for both access to MRI and CT scanners and further progress will be necessary if we are to deliver the vision of world class cancer services outlined in this strategy. For example OECD estimates suggest that in 2004, the UK had 5 MRI scanners per million of population compared to an international median of 6.7. Similarly estimates suggest that the UK had 7 CT scanners per million of population, compared to a median of 14.<sup>54</sup>

**11.15** The National Framework for the Development of PET-CT Services in England was published in October 2005 and recommended that provision should be made for 40,000 scans per annum for cancer patients across England by 2010. A series of initiatives have already been put in place to enable the NHS to reach this level. Currently 21,000 scans are undertaken each year and this figure will double when independent sector contracts become operational early in 2008. A UK PET-CT Advisory Board has been established which will keep the uses of PET-CT under review and ensure that there is a controlled expansion of these services.

**11.16** In keeping with the broad thrust of this strategy, we do not propose to set new targets for the further expansion of cancer related facilities. Instead, we will monitor the outputs and outcomes – both in terms of the numbers of procedures undertaken each year and in relation to the achievement of the waiting time standards outlined in earlier chapters. This will enable both providers and commissioners to benchmark local provision against national averages. The Department of Health will also

continue to benchmark progress in England against international good practice and advise commissioners accordingly. Commissioners will need to work with providers to ensure that they have appropriate capital investment strategies that enable older equipment to be replaced. Sufficient finance will be made available to the NHS as part of their general capital allocations to fund investment in new cancer equipment.

**11.17** In addition to the provision of modern equipment, attention needs to be given to the overall physical environment in which care is delivered. Cancer patients have to attend clinics, day case units and/or radiotherapy departments on multiple occasions over a period of weeks, months and years. Some of the day case attendances may take several hours, for example to receive a prolonged infusion of chemotherapy. The quality of the physical environment in which such care is delivered can affect a patient's overall experience of care. Some groups, for example children and young people, will have particular needs and should be treated in an environment appropriate to them.

**11.18** People affected by cancer deserve to be treated and supported in physical environments which meet high quality standards. Although the investment of recent years has improved the environment for patients and staff the improvement needs to continue and be sustained. **We will work with patient groups to develop a 'kitemark' for good cancer facilities. Commissioners will be encouraged to take the quality of the physical environment into account when making service planning decisions and information on the quality of facilities will be made available to patients through NHS Choices ([www.nhs.uk](http://www.nhs.uk)).**

### Good horizon-scanning

**11.19** Thanks to high quality research, the pace of change in cancer can be rapid. It is therefore vital that we have in place good quality horizon-scanning, enabling us to identify and plan for the opportunities and challenges of the future.

**11.20** **The expert groups convened to develop the site specific visions for cancer**

**services in 2012 have provided valuable insights into how services could and should develop over the next five years. However, these visions should not remain static.**

**We will therefore reconvene these groups at appropriate intervals to review progress, provide information on new developments and discuss emerging challenges.**

11.21 In addition to this we need to ensure that new technologies (such as drugs or other treatments) which could benefit cancer patients are identified and referred to NICE without delay. During the past year the Department of Health and NICE have established a new process for doing this. Potential technologies are identified by the National Horizon Scanning Centre and are initially assessed by a consideration panel convened by NICE and chaired by the National Cancer Director. Recommendations on priorities for technology appraisals from this and equivalent panels for other disease areas are then made to Ministers. Chapter 4 sets out the changes that will be introduced to this process for cancer medicines.

### High quality cancer research

11.22 Progress on cancer research in the UK has been impressive since 2000. The NHS Cancer Plan heralded the establishment of the National Cancer Research Institute (NCRI). Set up in 2001, the NCRI operates as an 'institute without walls.' It comprises 20 partners and is supported by a secretariat whose costs are reimbursed by the partners on annual basis. The partnership includes the Health Departments from all UK countries as well as Research Councils, the major charities that fund cancer research and the Association of British Pharmaceutical Industry (ABPI), together with cancer patients.

11.23 The NCRI has set up and maintains a database of current research in cancer in the UK, which enables analysis of strengths and weaknesses in the portfolio. Partners have worked together to prepare and publish authoritative reports on a number of topics and to put together funding consortia to enhance research in a number of areas, in particular:

- Prostate cancer;
- Radiotherapy & radiobiology;
- Prevention through lifestyle changes relating to smoking, diet, exercise and alcohol;
- Supportive and palliative care;
- Lung cancer and mesothelioma; and
- New imaging techniques, especially PET.

11.24 To date, these research initiatives are worth a total of £31 million, from government and charity funders over their lifetime. In addition, the Department of Health provides £15 million a year for the National Cancer Research Network (NCRN), which is an NCRI initiative. Over the period since NCRI was set up, the total annual government spend on cancer research through NCRI partners has risen from £105 million in 2002 to £137 million in 2006, an increase of 30%. Charity funding has increased from £152 million to £250 million over the same period. The government's funding for the NCRI does not include NHS service support for cancer research, which was reported by NHS organisations to have been worth approximately £130 million in 2006/7.

**11.25 In the coming years, NCRI will continue to respond to national priorities as set out in this strategy and to overcome weaknesses in the cancer research base in the UK. A five year plan, which will begin in April 2008, is currently in development and will be published in early 2008. The plan will take account of gaps in the research evidence base identified during the development of the Cancer Reform Strategy. NCRI does not fund research directly but will continue to encourage partners to work together on research in areas including:**

- **Developing and evaluating the interventions which promote earlier patient presentation and reduce professional delay in referral;**

- **Development of novel biomarkers for a variety of uses including diagnosis and treatment monitoring;**
- **Prevention and screening;**
- **Studies of rarer tumours;**
- **Understanding inequalities, including those due to ethnicity and gender and regional variations in outcomes; and**
- **Improving quality of life for cancer survivors.**

11.26 National Cancer Research Institute (NCRI) also facilitates research through jointly funded infrastructure initiatives, including:

- Experimental Cancer Medicine Centres for early phase trials and translational studies;
- The NCRN for phase III trials;
- The National Cancer Intelligence Network (NCIN) as a repository of NHS data about cancer;
- The NCRI Informatics Initiative; and
- The Confederation of Cancer Biobanks.

11.27 In addition to focusing on the need for new knowledge in these topics, NCRI is promoting the development of research tools and infrastructure, especially in informatics and biobanking. This national approach to the provision of resources will continue and will ensure that costs can be shared and standards both harmonised and driven upwards. Some ten million pounds has been invested in specific NCRI initiatives in these areas and much more is invested by individual Partners.

11.28 NCRI Partners will continue to foster the high quality basic science for which the UK is internationally renowned. Partners will also work together to ensure that discoveries are translated into new interventions as rapidly as possible.

11.29 Chapter 7 sets out how the NCRI will develop the NCIN to collect and disseminate information about the performance of services on improving public awareness, clinical outcomes and patient experience.

11.30 The transition from NTRAC, the former National Translational Cancer Research Network, to the network of Experimental Cancer Medicine Centres (ECMCs) took place in April 2007, involving new investment totalling £35 million over five years from the four Health Departments of the UK and Cancer Research UK. With Department of Health funding, NCRI has initiated a bi-annual series of forum meetings to encourage networking and collaboration in translational cancer research. These bring together scientists from a wide range of disciplines together with research nurses, data managers, industry scientists/executives and many others.

11.31 The NCRN was established in 2001. Since then it has met its target of doubling the number of patients entering clinical trials ahead of schedule. In the last five years the NCRN has tripled the number cancer patients entering trials and in each of the last two years England has had the highest per capita rate of cancer trial participation in the world. Following the success of the NCRN model, it has been replicated in other disease groups as part of the UK Clinical Research Network (UKCRN). Department of Health funding for the NCRN totalled £54 million in the first five years. Over the next five years it is likely to total over £77 million. NCRN plans for the future involve closer working with NICE and a greater focus on supporting high priority studies.

11.32 'Best Research for Best Health,' published in 2006, sets out the government's goals for research and development in the NHS.<sup>55</sup> Substantial progress has already been made on implementation and the National Institute of Health Research (NIHR), through which many of the initiatives will be delivered, has been established. Cancer forms an important part of the work of many of the NIHR Biomedical Research Centres.

11.33 Looking to the future, the Department of Health is supportive of plans for the National Cancer Intelligence Network, which will provide a valuable resource for research. **The Department of Health stands ready to fund and support high quality health services research using data generated by the NCIN.**

11.34 **The Department of Health also stands ready to fund targeted research to support areas of high need.** For example, on screening (chapter 3), the Department of Health is leading work on behalf of the NCRI to commission research on the feasibility of a UK trial of CT screening for lung cancer. The extension of the NHS Breast Screening Programme provides an opportunity to evaluate the number of additional lives saved. New screening technologies, particularly in bowel cancer and cervical cancer screening, will need to be properly evaluated. On imaging and radiotherapy (chapter 4) the academic community needs more support to design and implement high quality research trials. The Department of Health is therefore considering how best to achieve this.

## Clear national leadership, support and oversight

11.35 National leadership will remain important in maintaining progress on cancer and ensuring appropriate planning for the future.

11.36 The role of National Cancer Director was established in 1999. Over the past eight years this role has evolved to encompass both the development of cancer strategy and oversight of its implementation. Specific aspects of the role include:

- Providing advice to Ministers and the Department of Health on all aspects of cancer policy;
- Supporting SHAs, Primary Care Trusts and providers in the implementation of the Cancer Perform Strategy;
- Facilitating the spread of good practice;
- Monitoring progress;

- Liaising with arms length bodies who contribute to the cancer agenda (such as NICE, Healthcare Commission, National Patient Safety Agency, Monitor, NHS Institute); and
- Developing and strengthening partnerships with external stakeholders (such as cancer charities, hospices, Royal Colleges, industry and the cancer research community).

11.37 To fulfil these duties the National Cancer Director is supported by the Department of Health Cancer Policy Team, the Cancer Action Team (which is increasingly focusing on support for commissioners), the Cancer Services Collaborative Improvement Partnership (CSC-IP) (which largely provides support to providers) and the National Cancer Screening Programmes.

11.38 The roles undertaken by the National Cancer Director and the national cancer teams will be critical following the publication of this strategy. However, the emphasis on different activities will continue to change over time. For example, until recently the work of the CSC-IP has focused largely on helping provider services to reduce waiting times for cancer. In the future, the main emphasis of their work will be on supporting providers to reduce unnecessary hospital inpatient care and outpatient visits.

## Role of stakeholders

11.39 Over the past few years, cancer services have benefited from the development of successful partnerships with external stakeholders both at a national and local level. The voluntary sector, both through cancer charities and hospices, has played a vital role, as have partnerships with industry and the professions. The Department of Health has also benefited from the input of a wide range of health professionals, patients and NHS managers on numerous advisory groups related to specific aspects of cancer.

11.40 These partnerships have been particularly valuable in helping to shape the Cancer Reform Strategy. The groups set up to help inform the development of the Strategy have now completed their tasks and been disbanded.

However, the government is keen to retain the enthusiasm and commitment shown by external stakeholders and the benefit which comes from external scrutiny and expertise.

**11.41** We will convene a conference in the New Year for stakeholders in cancer policy, including those who contributed to the development of the Cancer Reform Strategy, to discuss the next steps in delivering the strategy, as well as how we can all contribute to its success.

### Assessing progress

**11.42 The government is committed to tracking progress on cancer to ensure that the aims of this strategy are achieved. The National Cancer Director will deliver annual reports on progress to Ministers to help enable an informed discussion with stakeholders.** These reports, which will be published, will assess overall progress on tackling cancer, as well as examining in more detail developments relating to a number of different forms of cancer each year. The National Cancer Director will work closely with the National Cancer Intelligence Network on the development of these reports. **An advisory board of stakeholders will be also convened to provide input to each annual report.**

**11.43** If we wish to have world class cancer services, then it will be necessary to compare our services with those of other countries. Furthermore there is much we can learn from the experience of others, sharing ideas, comparing outcomes and learning from good practice. As the NHS implements this strategy we will continue to track our progress in relation to other countries on issues such as survival and mortality, awareness, early detection, access to different forms of treatment, clinical outcomes, patient experience and costs. However, these comparisons are not simple and without careful consideration, could lead to false conclusions. We will therefore ask the NCIN to develop a framework for accurate comparison with other countries. In particular, we envisage collaborating closely with countries in Europe, the USA, Canada, New Zealand and Australia.





# Annexes

## Annex 1: Documents published alongside the Cancer Reform Strategy

Executive Summary of Cancer Reform Strategy	Power Point presentation on Cancer Reform Strategy
Summary of what the Cancer Reform Strategy means for patients	Summary of NICE products for cancer
Equality Impact Assessment	Visions
Glossary of cancer terminology	<ul style="list-style-type: none"> <li>• Bowel cancer;</li> </ul>
Impact Assessment	<ul style="list-style-type: none"> <li>• Brain and CNS cancers;</li> </ul>
Membership of Advisory Board	<ul style="list-style-type: none"> <li>• Breast cancer;</li> </ul>
Membership of working groups	<ul style="list-style-type: none"> <li>• Children and young people;</li> </ul>
<ul style="list-style-type: none"> <li>• Awareness and early detection;</li> </ul>	<ul style="list-style-type: none"> <li>• Cancer genetics;</li> </ul>
<ul style="list-style-type: none"> <li>• Clinical outcomes;</li> </ul>	<ul style="list-style-type: none"> <li>• Gynaecological cancers;</li> </ul>
<ul style="list-style-type: none"> <li>• Commissioning and levers for change;</li> </ul>	<ul style="list-style-type: none"> <li>• Haematological cancers;</li> </ul>
<ul style="list-style-type: none"> <li>• Costs and benefits;</li> </ul>	<ul style="list-style-type: none"> <li>• Head, neck and thyroid cancers;</li> </ul>
<ul style="list-style-type: none"> <li>• Patient experience; and</li> </ul>	<ul style="list-style-type: none"> <li>• Lung and mesothelioma;</li> </ul>
<ul style="list-style-type: none"> <li>• Service models/provider development.</li> </ul>	<ul style="list-style-type: none"> <li>• Prostate cancers;</li> </ul>
	<ul style="list-style-type: none"> <li>• Sarcoma;</li> </ul>
	<ul style="list-style-type: none"> <li>• Screening;</li> </ul>
	<ul style="list-style-type: none"> <li>• Skin cancers;</li> </ul>
	<ul style="list-style-type: none"> <li>• Upper Gastrointestinal cancers; and</li> </ul>
	<ul style="list-style-type: none"> <li>• Urological (excluding prostate) cancers.</li> </ul>

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