The NHS Cancer Plan
and the new NHS

Providing a patient-centred service

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The NHS Cancer Plan and the new NHS

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Foreword
by the Secretary of State for Health

In September 2000 we said we were making cancer a priority. The situation was far from ideal and many cancer patients were not receiving the treatment and care they should have been. In the NHS Cancer Plan we set out a ten-year national strategy to reorganise, standardise and rejuvenate cancer services so that we compare with the best in Europe.

We have made significant progress towards those objectives. As the latest figures show deaths have fallen by more than 12% in just six years. Last year, in our three year progress report – Maintaining the Momentum – we set out the evidence to show how services have improved and patients are being diagnosed, treated and cared for faster and better.

Since the publication of the three-year progress report on cancer we have published the NHS Improvement Plan. The NHS has undergone a period of intense change over the last seven years. One of the key principles of this change is improving the health of the population as a whole, targeting inequalities and promoting prevention as well as cure.

The Public Health White Paper, being published later this year, will tackle head on many of the behaviours that dramatically increase people’s risk of cancer. It will talk about how the NHS can enable people to lead healthier lives by giving them the information and support they need to change their behaviour. In the long term the best and most efficient way of beating cancer, both for individuals and in terms of NHS resources, has to be prevention.

The other key principle of this ongoing programme of change is reshaping the health services around the needs and aspirations of patients. This begins with giving people the best chance of recovery by detecting cancer early.

The NHS breast and cervical screening programmes are two of our biggest success stories. According to a study by the British Association of Surgical Oncologists published in May this year, over 95% of women who have had invasive breast cancer detected by screening are alive five years later. In the same month, the International Agency for Research on Cancer (IARC), part of the World Health Organisation, concluded that organised and quality controlled cervical screening, such as we have in this country, can achieve an 80% reduction in deaths from cervical cancer.

Because bowel cancer is the second biggest cancer killer I am announcing that from April 2006 we will begin a phased roll out of a National Bowel Cancer Screening Programme. Research has shown that the Faecal Occult Blood test (FOBt) method of screening can reduce mortality from bowel cancer, in the screening age group, by around 15% in men and women.

Speeding up the diagnosis and treatment of cancer is essential. This will be one of our primary focuses in the coming months. There are two extremely challenging waiting
times targets for December 2005 which we are determined to meet.

Mortality rates for all cancers continue to fall. We are ahead of the trajectory to achieve the target of a 20% reduction in the mortality rate from cancer in people under 75 by 2010. Within this mortality rates for two of the biggest killers – breast cancer in women and lung cancer in men – are falling more quickly in this country than anywhere else in the world.

We know we can’t rest on our laurels and assume the job is done. Much of the progress which has been made so far is thanks to the staff providing cancer services. They have readily and effectively examined the way they provide these services and made improvements too numerous to mention. If this progress is to continue then cancer must remain both a national and a local priority.

JOHN REID
SECRETARY OF STATE FOR HEALTH
Introduction
by the National Cancer Director

The *NHS Cancer Plan* was published just over four years ago. It is a long term, national strategy to prevent, diagnose and treat cancer; to reform the way cancer services are delivered; to standardise care and improve patient experience; to co-ordinate research and to invest in equipment and the cancer workforce.

Last year we published a comprehensive progress report to mark the third anniversary of the *NHS Cancer Plan*. This set out the significant progress made on cancer and acknowledged the challenges that lay ahead.

Since that report was published, further progress has been made on all aspects of the *NHS Cancer Plan*:

- Action plans have been developed to ensure implementation of Improving Outcomes Guidance.
- More patients are receiving new cancer drugs approved by NICE and measures have been introduced to reduce variations in usage.
- New guidance to improve the quality of supportive and palliative care services has been published. At a local level cancer networks have been developing action plans to implement this guidance.
- A new programme to enhance end of life care has been launched.
- Additional consultants in palliative medicine and more clinical nurse specialists in palliative care have been recruited with the additional £50 million allocated for palliative care.
- The cancer workforce continues to expand, and national training initiatives will deliver much needed additional capacity in key areas over coming years.
- More CT and MRI scanners and linear accelerators have been installed and a framework to establish PET scanning services across the country has been issued for consultation.
• The proportion of cancer patients entered into clinical trials continues to rise and the National Cancer Research Institute has announced major new initiatives on research into prevention and into supportive and palliative care.

Meeting the waiting times targets for December 2005 – that no urgently referred patients wait longer than two months until their first treatment and all patients are treated within a month of diagnosis – will be an enormous challenge.

We must also ensure that services continue expanding to deal with the rising incidence of cancer and that effective new technologies are introduced without delay.

In addition to meeting existing commitments those responsible for the delivery of cancer services face new challenges. The first is to reduce the gap in cancer mortality rates between areas with the worst health and deprivation and the country as a whole. This will require concerted efforts in deprived areas to reduce smoking rates and to improve early detection of cancer through raising public awareness and promoting earlier help seeking behaviour by patients with symptoms.

The second challenge will be to implement a national bowel cancer screening programme. This will require further expansion of endoscopy services, but will undoubtedly save lives.

The NHS has changed markedly in the four years since the NHS Cancer Plan was published. Primary Care Trusts, Strategic Health Authorities and, more recently, Foundation Trusts have been established. The independent sector is playing a larger part in the delivery of services. A new tariff based system of payment for services is being introduced. National standards and new national targets have been published.

The aim of this fourth anniversary report is to show how cancer fits in this ‘new’ NHS. The actions taken to tackle cancer map onto the four priority areas set out in the NHS Improvement Plan and National Standards, Local Action (published in July 2004). This report also outlines how the new drivers for delivery will ensure that the aims of the NHS Cancer Plan are achieved.

MIKE RICHARDS
NATIONAL CANCER DIRECTOR
Chapter 1
A healthier population – the importance of cancer

“... The NHS will become a health service, not just a sickness service, leading national
and local efforts to tackle the causes of ill-health and narrowing the gap between the
healthiest and the unhealthiest parts of the country.”

(The NHS Improvement Plan June 2004)

More than one in three people will be
diagnosed with a cancer in their lifetime and
one in four will die from cancer.

• In 2001 around 225,000 new cases of
cancer were diagnosed of whom
141,000 were aged less than 75 years.

• The total number of new cases is
increasing by 1.4% per annum. This is
mainly due to the ageing population,
screening and better diagnosis.

• Around 130,000 people die from cancer
each year of whom 65,000 are aged less
than 75 years.

• Four types of cancer account for over
50% of new cases: Lung (around 30,000
new cases in 2001); Breast (around
34,000); Bowel (around 27,000) and
Prostate (around 26,000). No other
individual cancer type accounts for more
than 9000 cases per annum.

Death rates continue to fall
The Government is committed to reducing
the death rate from cancer by 20% in people
under the age of 75 by 2010.

In meeting this target around 130,000
deaths from cancer will have been avoided
over the lifetime of the target.

There has been good progress in tackling
cancer in recent years. The most recent
figures (provisional data for 2001-03) show
that the death rate amongst people under
75 years has fallen by 12.2% from the
1995-97 baseline.

The death rate from breast cancer in women
and lung cancer in men is falling quicker in
this country than anywhere else in the world.
The fall in breast cancer mortality has
occurred despite considerable increases in
the number of people being diagnosed.
Cancer mortality target
Death rates from All Cancers in England 1993-2003 and target for the year ‘2010’
Persons under 75 (including provisional data for 2001/02/03)

3 Year Average Rates

TARGET: 20% minimum reduction from 1995-1997 baseline rate

Rates are calculated using population estimates based on 2001 census. Rates are calculated using the European Standard Population to take account of differences in age structure. Provisional rate for 2003 calculated using mid-year population estimates for 2002. ICD9 data for 1993 to 1998 and 2000 have been adjusted to be comparable with ICD10 data for 1999 and 2001 onwards.
Source: ONS (ICD9 140-209; ICD10 C00-C97)

Reducing inequalities in cancer mortality
Cancer incidence and mortality rates are higher in areas of social deprivation. This is mainly due to higher smoking levels and poorer diet. Later diagnosis due to lower uptake of screening and patients with symptoms waiting longer before going to see their GP also plays a part.

In the new Public Services Agreement (PSA) there is a challenging new target to tackle the social inequalities which exist in relation to death rates from cancer. The target is to achieve a reduction in the inequalities gap of at least 6% between the fifth of areas with the worst health and deprivation indicators and the population as a whole.
Cancer mortality inequality target
Death rates from All Cancers in England 1993-2003 and target and projections* for the year ‘2010’
Persons under 75

Rates are calculated using population estimates based on 2001 census. Rates are calculated using the European Standard Population to take account of differences in age structure. *Exceptional projection based on the ten years 1993-2002. Projections illustrated are the three year moving average of single year rates. ICD9 data for 1993 to 1998 and 2000 have been adjusted to be comparable with ICD10 data for 1999 and 2001 onwards.
Source: ONS (ICD9 140-209; ICD10 C00-C97)

This target will be met by helping Primary Care Trusts (PCTs), Trusts and Strategic Health Authorities (SHAs) to:

• maximise the numbers of people using stop smoking services
• encourage patients to present to their GPs earlier, without causing unnecessary anxiety
• increase the coverage of breast and cervical screening
• ensure breast screening is extended to 65-70 year-old women
• ensure the National Institute for Clinical Excellence (NICE) referral guidelines are followed in primary care
• improving access to diagnostic tests for GPs.
Preventing cancer
Well over half of all cancers are potentially preventable through measures to reduce smoking, improved diet and increase physical activity.

Smoking
Smoking is the most important cause of cancer and accounts for one third of cancer deaths.

The prevalence of smoking among adults is currently around 26%. The following actions are being taken to reduce this rate further:

- NHS Stop Smoking Services are available across the country.
- In the last full year (April 2003/March 2004) around 359,000 people had set a quit date. This compares with 124,100 people in 2002/03 – an increase of 65%.
- At the four week follow-up around 204,200 (57%) of those setting a quit date had successfully quit in 2003/04.
- Quit rates vary between SHAs and PCTs. Some of the most successful PCTs are in deprived areas. The Department of Health is working with these successful services to spread good practice.
- Regulations to end newspaper, billboard and magazine advertising, in-pack promotion direct marketing and most

People who accessed Stop Smoking Services and were still not smoking 4 weeks after quitting, by Strategic Health Authority England, 2003-04 (Provisional Figures)

sponsorship came into force in 2003. These can be expected to reduce smoking rates further in the future.

- Bigger and more direct warnings appeared on cigarette packets since January 2003.
- Misleading descriptors such as ‘light’, ‘mild’ and ‘low tar’ were removed from cigarette packs from September 2003.
- £39 million was allocated to a strengthened information and education media campaign with all-year media presence. This includes a new second hand smoke strand and new testimonials. During periods of TV advertising call levels to the NHS Stop Smoking Helpline average 4,000 per week and over 900,000 calls have been received to date. A website offering information and advice is also available and is being visited by, on average, 7,400 unique users each week.

Diet and Nutrition
Obesity is now recognised as a major risk factor for some cancers, particularly breast cancer, bowel cancer and renal cancer.

- The Department of Health is co-ordinating the Food and Health Action Plan. The Plan draws together all food and health activity across nine Government departments, key players from industry, NGOs, OGD and local authorities.
- Through the Big Lottery Fund £10 million has been made available to 66 PCTs to support Local 5 A DAY community initiatives. This increases access to and availability of fruit and vegetables within disadvantaged communities. This programme is now reaching over six million people.
- 330 organisations are now licensed to use the 5 A DAY logo, launched March 2003, including Safeways, Asda, Delmonte, Coca-Cola (fruit juice) and Bird’s Eye.
- Over one million 4-6 year olds in England now receive free fruit and by the end of 2004 all 4-6 year olds in England will be eligible.
- 27% of children and their families report that they now eat more fruit at home after their school joined the scheme.
- £2.2 million has been invested in the Food in Schools Programme, a joint venture between the Department of Health and Department of Education. Eight regional projects are testing strategies for improving the nutrition and diet of children. Results will be available for wider circulation from the beginning of 2005.
- The £142 million reform of the Welfare Food Scheme aims to improve access to a wider range of ‘healthy’ foods including fruit and vegetables, and to provide improved support for breastfeeding.

Physical Activity
Increasing levels of physical activity will help to reduce obesity and can directly reduce the risk of some cancers.

- Jointly with the Department of Culture Media and Sport, the Department of Health is developing a cross-government strategy to increase mass participation in physical activity and sport in England from 32% to 70% by 2020.
- Ten Local Exercise Action Pilots (LEAP), are underway across England supported by £2.6 million funding. Pilots, based in Neighbourhood Renewal Areas, will evaluate different PCT led community approaches to increasing levels of and access to physical activity. These will make
CHAPTER 1: A HEALTHIER POPULATION – THE IMPORTANCE OF CANCER

a significant contribution to the evidence base on what works.

- The Department of Health has co-funded, with the Countryside Agency and the British Heart Foundation, a pedometer loan pilot scheme. 10,000 pedometers have been given to 110 PCTs in areas of high deprivation as a motivational tool to encourage increased walking.

- There are over 700 GP exercise referral schemes prescribing physical activity to improve health and wellbeing.

**Early detection of cancer**

**National Breast Screening Programme**

Introduced in 1988, the NHS has the first and one of the most successful National Breast Cancer Screening Programmes in Europe.

- 1.3 million women in England were screened in 2002/03, at an estimated cost of £62 million.

- Nearly 10,000 cancers were detected, over half of which were small cancers which could not have been detected by hand.

- 95.8% of women who have had invasive breast cancer detected by screening are alive five years later (British Association of Surgical Oncologists May 2004).

- More than half of breast screening units have extended breast screening to women aged 65 to 70. Over 250,000 more women have been invited for screening since the extension began in April 2001.

In addition to extending the age range of the programme, the *NHS Cancer Plan* also announced that the current service would be upgraded by offering two x-ray views of each breast at each screening round. Research had estimated that this would lead to a 42% improvement in the detection of small breast cancers. Over 95% of local breast screening units have now implemented two-views, resulting in a 13% increase in the number of cancers detected between 2001/02 and 2002/03.

**National Cervical Screening Programme**

The National Cervical Screening Programme was introduced in 1988 and was the first such programme in Europe. It is directly responsible for a 42% drop in incidence in cervical cancer between 1988 and 1997.

In May 2004, the International Agency for Research on Cancer (IARC), part of the World Health Organisation, concluded that organised and quality controlled cervical screening can achieve an 80% reduction in the mortality of cervical cancer. Women aged 25 to 49 should be screened no more than every three years, and women aged 50 to 64 no more than every five years.

In July 2004, Professor Julian Peto and colleagues published a paper in The Lancet, *The cervical cancer epidemic that screening has prevented in the UK*. The paper concluded that cervical screening has prevented an epidemic that would have killed about one in 65 of all British women born since 1950 and culminated in about 6,000 deaths per year in this country. 80% or more of these deaths, up to 5,000 deaths per year, are likely to be prevented by screening.

About 100,000 of the 8 million British women born between 1951 and 1970 will be saved from premature death by the cervical screening programme.

In 2002/03, 81% of eligible women had a test result in the last five years. 3.7 million women were screened, 127,000 women were referred following abnormal results and 65% of those received treatment.
Last year plans to modernise the service were announced. Following research from Cancer Research UK, the frequency at which women are invited for screening is being standardised across England for the first time.

Following a government funded pilot study of Liquid Based Cytology (LBC), the National Institute of Clinical Excellence (NICE) concluded that this new technology should be rolled out across the NHS. LBC will reduce the number of unsatisfactory tests meaning that in any given year 300,000 women will not have to go through the anxiety of being re-tested.

It will take five years to implement LBC across England as staff who take and read the tests will have to be re-trained. The Department of Health is providing £7.2 million over the first two years to kick start this process.

**National Bowel Cancer Screening Programme**

In November 2002 the Government confirmed its commitment to introducing a National Bowel Cancer Screening Programme and work began to ensure that the necessary workforce would be in place.

In October 2003 the Department of Health announced that seven regional and three national endoscopy training centres would be established to train more people to carry out this vital diagnostic procedure and ready the NHS for a screening programme. By the end of 2004/05 there will be 345 newly trained endoscopists and 88 new trainers.

The screening methodology for bowel cancer screening is not clear cut. There are two possible methodologies – Faecal Occult Blood test (FOBt) and Flexible Sigmoidoscopy (FSIG). Research has shown that FOBt can reduce mortality from bowel cancer by around 15% in men and women aged 50 to 69 screened every two years. A major trial of FSIG is due to report in 2007. Preliminary findings are encouraging.

A formal appraisal of the different screening methods has recently been completed. This assessed the cost-effectiveness of the different approaches and the resources (both workforce and financial) likely to be needed for implementation.

Based on the findings of this appraisal a dual approach to bowel screening will be introduced from April 2006.

A phased introduction of FOBt amongst men and women in their sixties will be introduced from April 2006. At the same time, large scale pilots of FSIG will be undertaken involving people in their fifties. Final decisions have still to be made on exact ages. In this way a national screening programme develops using both screening methods, and a full programme can be introduced as soon as the research evidence permits.

The programme will be one of the first organised screening programmes for bowel cancer in Europe. It will also be the first cancer screening programme in England for both men and women.

**Public Health White Paper**

Further measures to improve the health of the population, which will reduce the risk of people developing cancer and other diseases, will be set out in the forthcoming Public Health White Paper.
“By 2008 the NHS will provide patients in England with services that compare well with world-class standards. Choice and responsiveness to individual needs will be a reality for all, not just the more affluent or the better informed. Waiting for treatment will have been reduced to the point where it is no longer the major issue for patients and the public.”

(The NHS Improvement Plan June 2004)

Improving access for cancer patients
Waiting for a specialist assessment, for diagnostic tests and for treatment can be a cause of major anxiety for patients who suspect they may have cancer and for their families. This anxiety can be compounded if there is uncertainty about the dates of appointments. For some patients with cancer prolonged periods of waiting may reduce the prospects of treatment having a successful outcome.

A series of staged milestones and targets, set between 2000 and 2005, were marked out in the NHS Cancer Plan. The NHS Improvement Plan and National Standards, Local Action make it clear that existing commitments for cancer will be achieved by December 2005.

Primary Care Trusts and their partners will be encouraged to plan for early reductions in key areas of diagnostic waits such as MRI, CT scans and endoscopy.

The NHS Improvement Plan sets out a commitment that by 2008 no one will wait longer than 18 weeks from GP referral to hospital treatment; waits from GP to initial outpatient consultation will not normally exceed six weeks and there will be even shorter waits for patients whose conditions require faster treatment.
CHAPTER 2: IMPROVING ACCESS AND CHOICE


<table>
<thead>
<tr>
<th>Year</th>
<th>Target Description</th>
<th>Progress 2003/04</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>Maximum two week wait from an urgent GP referral for suspected cancer to date first seen for all suspected cancers by end of 2000.</td>
<td>99.2% of people with suspected cancer seen by a specialist within two weeks of being referred urgently by a GP</td>
</tr>
<tr>
<td>2001</td>
<td>Maximum one month wait from urgent GP referral to first treatment for children’s cancers, testicular cancer and acute leukemia by end of 2001.</td>
<td>100% for children's cancer, 95% for testicular cancer, 99% for acute leukemia treated within one month of being referred urgently by a GP</td>
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<td></td>
<td>Maximum one month wait from diagnosis (date of decision to treat) to first treatment (start date) for breast cancer by end of 2001.</td>
<td>97% of women with breast cancer receiving first treatment within one month of diagnosis</td>
</tr>
<tr>
<td>2002</td>
<td>Maximum two month wait from urgent GP referral to first treatment for breast cancer by 2002.</td>
<td>97% of women with suspected breast cancer receive treatment within two months of urgent referral by their GP</td>
</tr>
<tr>
<td>2005</td>
<td>Maximum two month (62 days) wait from urgent GP referral to first treatment for all cancers by Dec 2005.</td>
<td>78% of all urgently referred patients with cancer treated within 62 days (based on available data for April-June 2004)</td>
</tr>
<tr>
<td></td>
<td>Maximum one month (31 days) wait from diagnosis to first treatment for all cancers by December 2005.</td>
<td>89.9% of all patients diagnosed with cancer treated within 31 days (based on available data for April-June 2004)</td>
</tr>
</tbody>
</table>

Achieving the 2005 waiting time targets will be a major challenge for Primary Care Trusts and acute Trusts.

To help them meet this challenge a National Cancer Waits Project has been established. Building on the successful approach adopted to reduce waits in Accident and Emergency departments and waits for elective orthopaedic surgery this approach has four key strands:

- **National Cancer Waits Project Plan**
  - 1. Increased focus
  - 2. Implementing best practice
  - 3. Robust performance management
  - 4. Targeted support
1. Increased focus

- The importance of the waiting times targets has been emphasised in meetings between the Department of Health and SHA Chief Executives.

- SHAs are now raising the profile with PCTs and NHS Trusts.

- The National Cancer Director and National Clinical Leads from the Cancer Services Collaborative (CSC) are engaging the support of the Royal Colleges and relevant professional societies.

2. Implementing best practice

- Over the past few years teams working with the CSC and the Modernisation Agency’s Endoscopy Programme have identified the key obstacles to achievement of the cancer waiting times targets. Importantly these teams have also identified potential solutions.

- Many patients with cancer require multiple tests and assessments between referral and treatment. It is essential that the processes are streamlined (to keep the number of individual steps to a minimum) and that unnecessary delays are eradicated at each step of these complex care pathways. Navigators or key workers can help to reduce waits.

- Waits for diagnostic tests (e.g. endoscopy, transrectal ultrasound biopsies and CT and MRI scans) are often too long. The endoscopy programme, the radiology service improvement team and the urology team within the CSC have all shown that these waits can be radically reduced.

- Waits for radiotherapy are too long in many centres. This is largely due to inadequate numbers of therapy radiographers. This is being addressed by doubling the number of radiotherapy training places – but this will take time. In the meantime the radiotherapy team of the CSC has shown how much can be achieved by streamlining the process of care.

- The experience from the CSC has been drawn together as “high impact changes”. This advice is available to assist Trusts and teams in service re-design.

3. Robust performance management

- From now on performance by individual Trusts will be assessed on a monthly, rather than a quarterly basis. The results will be fed back to SHAs, Cancer Networks, PCTs and the Trusts themselves.

4. Targeted support

- A tailored support programme, for a limited number of NHS Trusts is currently being developed, modelled on equivalent programmes for A+E and orthopaedic departments. The focus of this support will be on reducing waits for patients with colorectal and urological cancers where waits tend to be longest.

Choice for cancer patients

The NHS Improvement Plan sets out the commitment that patients will be able to choose four to five providers for planned hospital care form December 2005. By 2008 patients will have the right to choose from any health care provider which meets the Healthcare Commission’s standards and which can provide the care within the price that the NHS will pay.

Apart from the two week wait for urgently referred patients the principle of choice applies equally to patients with cancer (or suspected cancer) as it does to patients with other conditions. However, given the faster timescales for reducing waits for patients with cancer across the whole NHS, by 2006
waiting times may not be a major factor in choosing between one provider and another. Service quality, assessed through achievement of standards endorsed by the Healthcare Commission may be a more important driver.

The NHS is widening choice further so that it will not simply be about the providers of elective care. There will be greater choice for people who are terminally ill. The End of Life Care Initiative is described in Chapter Four.

Patients need to be empowered to make choices which meet their own needs and preferences. Provision of high quality information and good verbal communication are prerequisites for empowerment. Effective systems for booking appointments electronically are also needed. These will be implemented across the NHS.
Chapter 3
Delivering high quality, managed care for cancer patients

“The NHS needs to provide a much better service for patients with long term conditions and provide high-quality personalised care to meet their needs.”

(The NHS Improvement Plan June 2004)

Cancer is not one disease. Nor is the course of the illness the same for all patients.

- Some patients are cured of their cancer, returning to normal activity after initial treatment.

- Some patients have a prolonged period of remission after initial treatment, which is followed by a relapse which is incurable.

- Some patients experience multiple remissions and relapses with different treatments.

- For some patients the cancer is incurable from the point of diagnosis.

The NHS Improvement Plan identifies the need for personalised support for patients with long-term conditions. It says that while patients will need individually tailored care, they can be broadly divided into three groups requiring different levels of support. This model for providing the right services for the right patients can be usefully applied to services and care for people with cancer. Many patients will need all three levels of support at different times.

For cancer patients a great deal of work is already underway at each of these three levels, and this is being built on with new initiatives.
CHAPTER 3: DELIVERING HIGH QUALITY, MANAGED CARE FOR CANCER PATIENTS

The right services for patients

Level 1 – Self Management

Healthy people – preventing cancer
Self management can mean taking appropriate action to minimise the risk of getting cancer. For example stopping smoking; maintaining a healthy weight, taking physical exercise and avoiding excessive exposure to sunlight.

Work on prevention – NHS Stop Smoking Services, diet and nutrition and physical activity – is detailed in Chapter 1.

For the second year running the Department of Health has provided funding to Cancer Research UK to develop their SunSmart campaign which raises awareness of the dangers of excessive exposure to sunlight and provides information around reducing the risk of skin cancer.

Healthy people – detecting cancer before symptoms develop
Self-management can also involve taking up screening opportunities to ensure that cancer is detected early.

For breast and cervical screening women who are invited for screening are also sent an information leaflet which helps them make an informed choice about taking up that invitation.

Information around the advantages and disadvantages of the Prostate Specific Antigen (PSA) test to detect prostate cancer are more complex. Through the Prostate Cancer Risk Management Programme all GPs are now able to counsel men on the advantages and disadvantages of the test and their various treatment options should high PSA levels be detected.
People with cancer
For people with cancer self-management is facilitated by being provided with timely and appropriate guidance and support around diagnosis and treatment options (see Chapter 4).

Level 2 – Disease Management
Much of the focus on improvement in cancer service delivery over recent years has been on disease management.

It will never be possible, or indeed desirable, to have identical services across the country. Services will need to take into account the needs and priorities of their local populations. However, it is important that there is consistency across the country in terms of access and quality of services.

NICE guidance on services
The Department of Health and NICE have developed a comprehensive package of national guidance (Improving Outcomes Guidance) on services which are most likely to improve outcomes for different types of cancer. This guidance is aimed at helping those involved in planning, commissioning, organising and providing cancer services.

Seven pieces of guidance related to specific cancers have already been published in this series covering breast, lung, colorectal, gynaecological, upper GI, urological and haematological cancers. Five more are in preparation covering rarer cancers – head & neck, sarcoma, skin, brain & central nervous system and child & adolescent cancers.

All cancer networks are producing action plans, containing costings and milestones, setting out how they intend to implement the guidance over a three year period.

Each of the NICE guidance reports emphasise that Multi Disciplinary Team (MDT) working is vital if we are to continue improving the overall experience of cancer patients. MDTs lead to improved communication between professionals involved and patients are therefore more likely to receive better continuity and co-ordination of care through all stages of their disease and better advice on appropriate treatment.

A survey by Dr Foster to inform their Good Hospital Guide 2004 indicated that 100% of breast cancer patients, 97% of lung cancer patients, 94% of upper GI cancer patients and 99% of bowel cancer patients are now being cared for by MDTs.

Chemotherapy
NICE has already appraised 16 chemotherapy drugs for a wide range of cancer types. The large majority of these drugs have received a positive appraisal and thousands of cancer patients are benefiting as a result.

In June 2004 the National Cancer Director published his report into variations in the usage of NICE recommended cancer drugs throughout the country. The reasons for the variations were complex but do not appear to be associated with direct funding restrictions on the use of these drugs. Instead the main impact on usage appears to be constraints in service capacity and differences in clinical practice.

Action already underway to reduce variations includes:

• bringing forward the introduction of electronic hospital prescribing to 2006 from 2008-10. This will allow patterns of low prescribing of particular drugs to be identified and addressed.

• entering into a new agreement with a commercial firm (IMS Health) to give the NHS access to better data on current prescribing patterns, as an interim measure until e-prescribing is introduced.
• development of a chemotherapy capacity planning model to help the NHS plan for the impact of new guidance on their chemotherapy services.

• SHAs, working with their PCTs and cancer networks, have produced plans to address the findings of the report where their usage was significantly below the national average.

Level 3 – Case management

Many clinical nurse specialists working in cancer or palliative care can be considered to have a ‘case management’ role, working with individual patients to enhance their ability to cope with their disease and helping to ensure that their care is well co-ordinated.

The number of clinical nurse specialists in different aspects of cancer care has increased markedly e.g. community-based palliative care nurse specialists, hospital-based palliative care nurse specialists, site-specific cancer nurse specialists and chemotherapy nurse specialists. In fact nurse specialists are almost certainly the largest single specialist group in the cancer workforce.

Nurse specialists in each of these groups have important roles in relation to the provision of information and support to cancer patients. They also have expertise in a specific area e.g. pain control and end of life care, chemotherapy, and knowledge of treatments for specific cancers.

Maintaining the Momentum, the progress report published to mark the third anniversary of the publication of the NHS Cancer Plan, set out a commitment to develop a number of primary care nursing pilots. In September 2004 we launched a new £6 million programme – now called the Integrated Cancer Care Programme – which will develop and deliver a model to help patients better navigate the health system, particularly the transition from primary to secondary care, and make positive decisions to suit their personal circumstances.

Nine pilot sites have been selected for this programme. These are:

• Haringey PCT
• Halton PCT
• Poole PCT
• Derbyshire Dales and South Derbyshire PCT
• Harrow PCT
• Selby and York PCT
• Herefordshire locality
• East Berkshire locality
• Portsmouth and South East Hampshire locality covering Fareham and Gosport, Portsmouth City and East Hampshire Primary Care Trusts.
Chapter 4
Improving the experience of cancer patients

“Expanding choice and developing a personalised service for patients depends on giving patients a stronger voice. Where patients choose to go will be important, as it will affect where resources go and which providers thrive. But there will also be a greater readiness, nationally and locally, to seek and listen to the views of patients and to act on them.”

(The NHS Improvement Plan June 2004)

A key aim of the NHS Cancer Plan is to ensure that patients get the best possible support and care as well as the best possible treatment. Over the past year major steps towards achieving this goal have been taken through:

- the publication of NICE guidance on supportive and palliative care
- local action planning to implement the guidance
- national initiatives related to information delivery, communication skills training and end of life care
- a survey conducted by the National Audit Office to assess progress over the past four years.

NICE guidance on supportive and palliative care

The supportive and palliative care guidance, published by the National Institute for Clinical Excellence (NICE) in March 2004, provides evidence-based recommendations on those service models most likely to lead to high quality care and services.

The guidance applies to all cancer patients and their carers and covers aspects such as co-ordination of care; communication; information; psychological support services; specialist palliative care; general palliative care; social support services; rehabilitation; complementary therapy services; spiritual support services; carer and bereavement support services and user involvement.

In September this year networks submitted their action plans for implementing the guidance including local targets to achieve compliance with the forthcoming quality measures on supportive and palliative care.
Better information for patients

A key recommendation of the NHS Cancer Plan was that all patients and carers should have access to a range of information materials about cancer and cancer services throughout the course of their illness. This should be high quality, accurate, culturally sensitive, specific to local provision of services, free at the point of delivery and timely.

The Coalition for Cancer Information (CCI) was formed in June 2002 to take this work forward. The CCI brings together producers and consumers of cancer information from national voluntary organisations – including Macmillan, Breast Cancer Care, CancerBACUP and Cancer Research UK – the National Cancer Research Institute, the National Health Service and the Department of Health.

Development of high quality information materials is not an end in itself. These materials (booklets, leaflets, videos etc) need to be made available to patients as and when they want them.

A major project to improve delivery of information to patients is being led by the Patient Experience Team of the Cancer Services Collaborative Improvement Partnership. Based on successful innovations in Leicester and in Lancashire and South Cumbria, all cancer networks are being asked to develop information protocols for patients with different cancer types. Workshops involving clinical nurse specialists, patients and carers are being held by cancer networks to develop these information protocols – so that information which meets the needs of patients is consistently available across a network.

Case study

**Hull & East Yorkshire Hospitals NHS Trust case study:**

Hull and East Yorkshire Hospitals NHS Trust have developed and installed a family information point. New touch screen technology allows patients, carers and staff to access local and national information about cancer treatment and support. A print facility allows patients to take home information relevant to their pathway. This development means that all 800 cancer patients and carers can access information that is relevant to their specific needs at a time that suits them.

Communication

High quality research has demonstrated the effectiveness of communication skills training for senior clinicians working in the field of cancer.

In association with the NHSU, the Department of Health is working to develop accredited advanced communication skills training courses for senior clinicians working with cancer patients.

The training focuses on key and sensitive areas of communication, including conveying complex information, breaking bad news and handling difficult and distressing situations. It will also enhance the confidence and team working skills of clinical staff.

The aim is to develop a cascade model whereby recognised leaders in the field of communication skills train facilitators to run courses according to a model that has been shown to be both effective and highly acceptable to participants. The facilitators who may be senior cancer clinicians
themselves or educators, will then train other senior healthcare professionals who will then train more junior staff locally.

The development of the training programme is being led, on behalf of the NHSU, by recognised experts from Cancer Research UK and Marie Curie Cancer Care. The first phase of development has been completed. Over the coming year a larger number of facilitators will be trained to enable rollout of the programme across the country.

User involvement in shaping cancer services

In 2001 the Cancer Partnership Project funded jointly by Macmillan Cancer Relief and the Department of Health was launched to implement the Cancerlink model of user involvement. This involved well-trained and supported health service users and health professionals facilitating user involvement within cancer networks by working together to influence service planning and delivery.

During the course of the project, 30 out of the 34 cancer networks established network level partnership groups. About 25 additional Trust based ‘locality’ groups were set up and 26 facilitator posts were created to service these groups. The facilitators were supported by Macmillan through a support programme which includes training, information and sharing best practice.

The project has now been independently evaluated and the Department of Health and Macmillan have disseminated the messages in the evaluation report.

End of Life Care Initiative

Improving end of life care for all patients, regardless of diagnosis, was heralded as a priority in Building on the Best: choice, responsiveness and equity in the NHS (December 2003). A total of £12 million (£4 million in each year over the three years to 2007) has been provided to train staff who care for patients at the end of life – in care homes, at home or in hospital.

The End of Life Care Initiative builds on the excellent work done in the field of cancer. The programme will use, and further develop, three existing tools:

- the Gold Standards Framework, which has already been introduced in over 1,000 general practices through a programme funded by Macmillan Cancer Relief. This framework enables all relevant personnel within a practice to identify patients who are approaching the end of life; to assess their needs; to plan their care and to communicate effectively with other health professionals.

- the Liverpool Care Pathway, which focuses on care provided in the last days of life and enables staff in any care setting to plan care for patients and their relatives.

- the Preferred Place of Care tool, developed by staff in the Lancashire and South Cumbria cancer network to facilitate discussions between patient and staff about where they would prefer to be cared for as the end of life approaches.

The End of Life Care Initiative, chaired jointly by the National Cancer Director and the National Director for Older People’s Services, will be managed through the 28 Strategic Health Authorities.
CHAPTER 4: IMPROVING THE EXPERIENCE OF CANCER PATIENTS

Monitoring progress: patient surveys

The first ever national cancer patient survey was conducted in 1999/2000 and published in 2002. It provides a useful baseline for monitoring changes in patient experience of care.

In general, patients were very positive about their care. Around 80% reported that they were treated with dignity and respect at all times and 86% had trust and confidence in doctors. Nearly 90% reported that they were involved as much as they wished in clinical decision making.

The National Cancer Patients Survey did, however, show areas where improvement is needed. In general patients from minority ethnic groups reported less favourably than others on the care they had received. Differences were also observed between patients with different types of cancer. Breast cancer patients generally reported better care than others. Within each tumour type there were significant variations between NHS Trusts in patient reports of the quality of care.

A further analysis of data from the National Cancer Patient Survey, published in 2004, indicates that several individual factors contribute to patients feeling that they have been treated with dignity and respect. These include: the quality of information and communication from staff; the perception that pain had been managed as well as possible; privacy during discussions and examinations and cleanliness of the hospital environment. We know from other patient surveys conducted in the NHS that the perception of being treated with dignity and respect is very closely related to overall satisfaction with care.

The National Audit Office (NAO) is currently conducting a further survey of cancer patients, using many of the items from the 1999/2000 survey. Around one third of NHS Trusts are participating in this survey, compared with all NHS Trusts in England in the earlier survey. The NAO survey should, however, give an indication of whether progress has been made in the past four years.
“The new NHS will be incentivised to deliver for patients more effectively.”
(The NHS Improvement Plan June 2004)

“The NHS Improvement Plan takes us into the next phase of reform of the health service. It sets a vision of 21st century health care and improved health. This vision should take precedence over old ways of doing things and institutional barriers, where these stand in the way of improving services to people. Organisations are expected to challenge the past, use innovation and creativity to determine new local solutions, and set new horizons for local services”.

Sir Nigel Crisp, Chief Executive of the NHS

The NHS has undergone a radical transformation since the NHS Cancer Plan was published four years ago. More money is being invested in healthcare than ever before (£67.4 billion in 2004/05), the workforce is expanding, new facilities are coming on stream and the way in which services are delivered has been reformed.

Increased investment

Funding
The NHS Cancer Plan promised an additional £280 million in 2001/02; rising to £407 million in 2002/03 and £570 million in 2003/04. The tracking investment exercise carried out in 2003 showed expenditure of just over £406m for 2002/03 and a similar tracking investment exercise carried out this year is expected to show spending for 2003/04 in excess of £570 million.

Cancer workforce
The NHS Cancer Plan promised an extra 1,000 cancer specialists by 2006 - an increase of nearly a third based on the 1999 baseline. Six clinical groups were included in these figures: clinical radiology, histopathology, haematology, clinical oncology, medical oncology and palliative medicine.

By June 2004 975 extra consultants were in posts in these six specialties, so the NHS Cancer Plan commitment should definitely be met.
Workforce expansion (September 1999 – June 2004):

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Increment</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiology</td>
<td>+352</td>
<td>23%</td>
</tr>
<tr>
<td>Histopathology</td>
<td>+239</td>
<td>29%</td>
</tr>
<tr>
<td>Haematology</td>
<td>+122</td>
<td>24%</td>
</tr>
<tr>
<td>Clinical Oncology</td>
<td>+76</td>
<td>25%</td>
</tr>
<tr>
<td>Medical Oncology</td>
<td>+85</td>
<td>77%</td>
</tr>
<tr>
<td>Palliative Medicine</td>
<td>+101</td>
<td>107%</td>
</tr>
<tr>
<td>General surgery</td>
<td>+345</td>
<td>27%</td>
</tr>
<tr>
<td>Cardiothoracic surgery</td>
<td>+58</td>
<td>32%</td>
</tr>
<tr>
<td>Respiratory Medicine</td>
<td>+245</td>
<td>71%</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>+281</td>
<td>72%</td>
</tr>
<tr>
<td>Urology</td>
<td>+120</td>
<td>31%</td>
</tr>
</tbody>
</table>

In addition there are 848 (7.8%) more diagnostic radiographers and 166 (11%) more therapy radiographers since 1999. The introduction of assistant practitioner roles across these services are also increasing capacity.

By the end of 2004/05 there will be 345 newly trained endoscopists and 88 new trainers.

Cancer Equipment/Facilities
Investment in new and replacement equipment is helping to improve reliability and access to diagnosis and treatment for many cancer patients.

Since January 2000 the following equipment has been delivered to the NHS (including Big Lottery Fund, local NHS and Department of Health funded machines):

- CT scanners 223 (168 replacements; 55 additional)
- MRI scanners 113 (56 replacements; 57 additional)
- Linear accelerators 104 (76 replacements; 28 additional)

The equipment is being provided where it is needed most. Two out of every three linear accelerators has been allocated to cancer centres in the north of England to overcome historic inequalities in investment. Also, additional CT and MRI scanners have been provided to local populations which have had poorer access.

In the twelve months since the third anniversary of the NHS Cancer Plan additional and replacement MRI and CT scanners have been delivered to:

- North Cumbria Acute Hospitals NHS Trust,
- Christie Hospital NHS Trust,
- Gloucestershire Hospitals NHS Trust,
- West Hertfordshire Hospitals NHS Trust,
The large majority of the staff involved in the Modernisation Agency’s diagnostic and cancer programmes are already working within the NHS. However, a core national team ensures consistency and spread of good practice between cancer networks and SHAs. This national team is now being integrated with the Cancer Action Team, which reports to the National Cancer Director, in readiness for the forthcoming changes to the Modernisation Agency.

Service redesign and the experience gathered by the Modernisation Agency teams will be central to the achievement of the December 2005 cancer waiting times targets.

**Information**

Information about cancer treatment is a powerful lever for improving service quality. Significant improvements have been made in the collection of information about different aspects of cancer over the past few years.

- The quality and timeliness of information collected by cancer registries has improved as have their links with cancer networks. Very soon online analytical information facilities and reports will be available electronically to registered NHS users through a new Cancer Information Service (CIS).
- Information on structure and processes of care is being collected through the peer review programme.
- Information on patients’ views of the care they receive is available from the National Cancer Patients Survey. Responsibility for this has now been transferred to the Healthcare Commission.
- Information on cancer related activity is collected through Hospital Episode Statistics (HES) which provides information on admitted patient care delivered by NHS
hospitals in England from 1989 to the present time.

- Information on cancer waits is being collected through a new cancer waiting times database.

However, much more can be done to collate and utilise the information that is being collected for service planning and monitoring. Collection of case-mix adjusted data is essential if valid comparisons are to be made between healthcare organisations. The National Clinical Audit Support Programme, which uses the national cancer dataset will provide such case-mix-adjusted data. Responsibility for this programme has now been transferred to the Healthcare Commission.

Changes to the NHS
Alongside the expansion of healthcare, major changes are occurring in the organisation of the health service. ‘Shifting the Balance of Power’ heralded the introduction of Strategic Health Authorities and Primary Care Trusts and the first steps in the devolution of responsibility to the frontline and away from the centre. Around 80% of NHS funds are now allocated to Primary Care Trusts.

Greater freedoms are now being given to NHS healthcare providers through the establishment of Foundation Trusts. There is greater plurality of service provision through the introduction of services managed by the independent sector. A new tariff-based system of payment for services – Payment by Results – is being phased in.

The NHS is moving away from a system that is mainly driven by national targets to one in which:

- standards are the main drivers for continuous improvements in quality
- there are fewer national targets
- there is greater scope for addressing local priorities
- incentives are in place to support the system
- all organisations locally play their part in service modernisation.

The rest of this chapter describes how the new system will deliver the changes needed to achieve the Government’s goals for cancer.

Improving partnership working
The major strides which have been taken to improve partnership working for cancer were set out last year in the three year progress report on the NHS Cancer Plan. Further progress has been made in the past year.

At a national level advisory groups have now been set up for three of the common cancers – prostate, bowel and lung. Each of these groups is chaired by the National Cancer Director and brings together key stakeholders from the NHS and the voluntary sector. These groups are complemented by the Coalition for Cancer Information and the
National Partnership Group on Palliative Care, which cover issues common to patients with all forms of cancer.

The NHS Cancer Plan made clear that networks were the vehicle for the delivery of the plan at a local level. Over the past year networks have continued to have a critical role in the planning and monitoring of cancer services delivery. This has included the development of Action Plans with firm milestones for the implementation of Improving Outcomes Guidance published by the Department of Health and more recently by NICE.

Cancer networks are partnerships involving multiple local organisations including PCTs, NHS Trusts, Foundation Trusts and voluntary sector providers (for example, hospices). They have been extremely successful in bringing together local stakeholders, clinical managers and patient groups. However, they are complex organisations and some of the member organisations (for example, PCTs) are still relatively young. To be effective the various partners need to agree on governance arrangements so that their duty of partnership to each other is clear.

The Department of Health and the Chief Executives of Strategic Health Authorities are aware that some networks are struggling to adapt to the new environment in the NHS. It has therefore been agreed that SHA Chief Executives and National Clinical Directors will work together to consider how networks (for cancer and other conditions) can best be supported and sustained.

**Standards to drive quality improvement**

Over the past eight years a major programme of work has been undertaken to develop evidence-based guidance for cancer. This programme is now co-ordinated by NICE. It has resulted in the publication of Improving Outcomes Guidance for individual cancers (Chapter 3) and for supportive and palliative care (Chapter 4).

These guidance documents have formed the basis of the development of measures against which individual services and cancer networks can be assessed. A new Manual for Cancer Services which sets out these measures was published in July 2004.

Building on the very positive evaluation of the cancer peer review appraisal visits undertaken in 2001, a national peer review programme is being relaunched this year. All cancer networks and their provider organisations will be appraised through a three year rolling programme.

The cancer specific measures map onto the seven domains of the new national standards. Importantly it has been agreed that the cancer peer review programme will be recognised as a partner organisation by the Healthcare Commission. The findings from cancer peer review will be passed to the Healthcare Commission and will be available for use in the context of annual reviews of healthcare organisations. Formal consultation on the Healthcare Commission’s intended approach to reviewing healthcare organisations against national standards will start later this year.

**Targets**

Although there are now fewer national targets than in the past, the public service agreement (PSA) target to reduce cancer mortality by 20% in people under 75 years by 2010 has been retained. In addition a new inequalities target relating to cancer mortality has been introduced (Chapter 1).

The contributions expected from individual SHAs to the overall achievement of these targets will be set out following the forthcoming guidance on local delivery planning.
**National standards, local action** makes it clear that a range of existing commitments detailed in the 2003-2006 planning round have to be delivered by the target dates, and performance has to be maintained at target level thereafter. Performance against these existing commitments will be covered by Healthcare Commission assessments which will inform performance ratings. For cancer the following existing commitments are directly relevant:

- ensure a maximum one month waiting time from diagnosis to treatment for all cancers by Dec 2005
- achieve a maximum two month wait from urgent referral to treatment of all cancers by Dec 2005
- 800,000 smokers from all age groups successfully quitting at the four week stage by 2006.

**Local priorities**
Although cancer is a national priority for which national targets and commitments have been set, different localities will face different additional priorities relating to local demographic patterns and other factors. It is important that localities should have the freedom to set themselves challenging local targets to address local needs. To assist localities in defining metrics when setting local targets, a set of ‘Better Metrics’ is currently under development.

**Incentives**
The new NHS and social care system will be incentivised to deliver better services for patients. Developments are now being made across three broad areas:

- independent performance assessment by the Healthcare Commission and CSCI
- a new system of financial incentives
- the development of commissioning.

The Healthcare Commission is currently developing assessment criteria which it will use to determine whether core standards have been met and to judge progress against developmental standards. Consultation on these assessment criteria, some of which will be directly relevant to cancer, is expected to commence shortly. The performance of PCTs, Trusts and NHS Foundation Trusts for the year 2005/06 will be assessed on this new basis.

A new tariff-based financial system, Payment by Results, is being introduced across the NHS. Full implementation will take place by 2008. For cancer this involves the development of Healthcare Resource Groupings (HRGs) related to key areas such as chemotherapy, radiotherapy and palliative care. Consideration also needs to be given to classification and tariff-setting for complex cancer surgery in order to incentivise the delivery of high quality care. Until the new HRGs are developed certain cancer services, such as chemotherapy, are excluded from Payment by Results. For other specialised cancer services, adjustments to the existing tariff will be made pending the delivery of the revised HRGs.

The importance of PCTs making full use of commissioning levers is emphasised in **National standards, local action**. Some aspects of cancer care are appropriately commissioned by individual PCTs. Other aspects (for example, complex cancer surgery, radiotherapy and chemotherapy) will be most effectively commissioned by PCTs working together through cancer networks. Cancer networks are well placed to plan and monitor service delivery for populations which involve several PCTs.
The NHS Cancer Plan and the new NHS

Providing a patient-centred service