



## Improving Cancer Services

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# IMPROVING CANCER SERVICES

## Health Value for Money Cancer Reports

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The Health Value for Money team looks at the Department of Health and related bodies. The Team has recently undertaken a series of three studies into the provision of cancer care by the Department of Health, the summaries of which are contained within this document:

- The NHS Cancer Plan: A Progress Report (published March 2005)
- Tackling Cancer: Improving the Patient Pathway (published February 2005)
- Tackling cancer in England: saving more lives (published March 2004)

Full versions of these reports are available to download from our website at <http://www.nao.org.uk/publications/index.htm>. You can also get details of work in progress at <http://www.nao.org.uk/publications/workinprogress/index.htm>.

The Health Value for Money team's future work programme includes examinations of the NHS's National Programme for Information Technology, stroke services, staffing issues and out of hours GP services.

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## EXECUTIVE SUMMARY

Tackling cancer in England: saving more lives



# Summary

- 1 More than one in three people in England will develop cancer at some point in their life. One in four people in England will die from it. There are over 220,000 new cases per year in England, and 128,000 deaths. The NAO is examining NHS cancer services in England in a suite of three studies. This study, on whether NHS cancer services are leading to better survival and lower mortality from cancer, will be followed by one on the patient's experience of cancer care and one on the development and implementation of all aspects of the NHS Cancer Plan.
- 2 In the early 1990s England suffered high cancer mortality rates and low rates of long-term survival compared with other European countries. The first step in responding to this was the 1995 Calman-Hine report. The 2000 NHS Cancer Plan built on this and was a comprehensive strategy to tackle cancer in England. The main aims of the NHS Cancer Plan are: to save more lives; improve support and care for patients; tackle health inequalities; and build for the future through expansion of the cancer workforce, investment in facilities and research and preparation for the genetics revolution.
- 3 In this study we examine whether cancer services are saving more lives across England and in relation to other countries. We concentrated in particular on the four cancers that cause the most deaths: breast, lung, bowel and prostate.
- 4 The Department of Health (through the NHS Cancer Plan) identified a number of key challenges in relation to saving lives from cancer. These are:
  - To change lifestyles which increase levels of cancer, including smoking and diet;
  - To expand cancer screening programmes where it is clear that they will save lives;
  - To detect cancer earlier and heighten public awareness of symptoms;
  - To identify people with suspected cancer in general practice and have them assessed promptly by specialists;
  - To speed up diagnosis; and
  - To ensure the most appropriate treatment is available to all.
- 5 The Department of Health has set out a programme to build capacity through additional facilities and an expanded workforce in order to meet these challenges. This study considers actions being taken in relation to the areas above by drawing on a wide range of published and unpublished data for this country and overseas, advice from experts, and surveys of Networks, GPs and cancer consultants.

## Cancer survival and death rates are improving in England

6 To measure England's performance in saving the lives of cancer patients it is necessary to look at three measures - incidence, mortality and survival<sup>1</sup>:

- Incidence The number of cancers which occur each year in a population of given size<sup>1</sup>.
- Mortality The number of people in a population of given size who die from cancer each year.
- Survival How long patients with a given type of cancer live on average after diagnosis - the proportion alive after five years is a standard measure.

7 Between 1971 and 2000 cancer incidence overall increased by 31 per cent (21 per cent for men and 39 per cent for women). This reflects in part more comprehensive collection of data on the occurrence of cancer and in part increases in several different cancer types such as prostate cancer in men, lung and breast cancer in women, and melanoma in men and women.

8 The reasons for increases in incidence are not fully understood although lifestyle factors such as trends in smoking and exposure to sunlight will impact on certain cancers. It should also be noted that, although the overall cancer incidence has risen, there has been a reduction in incidence in certain cancers such as stomach cancer. Again the reasons for this are not fully understood.

9 Despite the rise in incidence, mortality has fallen by 12 per cent (18 per cent for men and 7 per cent for women) between 1971 and 2002, mainly due to the reduction in lung cancer in men and better detection and treatment of breast cancer in women.

10 Five-year survival rates for all cancers diagnosed in the early 1990s (which is the latest data available for all cancers) were 36 per cent for men and 49 per cent for women. Whilst survival is improving for men and women in all socio-economic groups, survival rates for the better off have improved more than they have for those less well off.

11 England is continuing to improve on past performance in tackling the major cancers:

- Breast cancer. Incidence rates have continued to rise in the last 20 years, chiefly among more affluent women, while mortality rates fell by one quarter. In 1970 the 5-year survival rate was around 50 per cent. It is now approaching 80 per cent for women diagnosed in the latter half of the 1990s;
- Lung cancer. In the absence of adequate tests to detect early-stage lung cancer, trends are determined by smoking patterns. The highest recorded level of smoking among men in the UK was 82 per cent in the first national survey in 1948. Incidence and mortality rates for men have fallen sharply since peaking in 1974. The number of women smoking peaked in the late 1960s, though at much lower levels than men. Incidence of lung cancer has risen by 76 per cent for women between 1971 and 2000, while mortality rates are falling slightly after peaking in 1994. Lung cancer 5-year survival rates are poor and have been largely static over time;

<sup>1</sup> Incidence and mortality rates are expressed in this report as cases per 100,000 of the population, standardised for age to allow comparison between populations with different age structures. Cases are standardised either to the European standard population, indicated by an (E), or the World standard population, indicated by a (W). Survival rates are expressed as the percentage of those diagnosed who are still alive after five years. In this report we have used relative, rather than absolute, survival rates. Relative survival rates allow for the fact that, had patients not had cancer, there is a possibility that they might have died from some other cause in the five year period.

- Bowel cancer. Incidence rates have risen very slowly for two decades, while mortality rates have fallen by over 25 per cent. 5-year survival rates have risen steadily to nearly 50 per cent; and
  - Prostate cancer. The introduction of the Prostate Specific Antigen test to indicate the possible presence of prostate cancer has accentuated existing trends to increase reported incidence rates by half since 1980. Mortality has fallen slightly since peaking in the mid 1990s and 5-year survival rates have risen by two thirds since the early 1990s to over 60 per cent.
- 12 Cancer mortality varies widely within England, with higher rates in areas with high levels of deprivation. This is largely due to differences in incidence rates for lung cancer, which in turn are related to smoking rates. Reductions in mortality have been observed in recent years in almost all parts of the country. However, the degree of improvement has not been uniform. The rate of progress does not appear to relate to levels of affluence or deprivation.
  - 13 For each of the four major cancers there are considerable variations in incidence and mortality between strategic health authorities (SHAs). These variations are widest for lung cancer where incidence and mortality in the worst affected SHA are roughly twice that for the least affected SHA. Mortality rates may vary between areas with similar level of incidence. Survival rates for the major cancers consistently favour London and the south of England.
  - 14 England's position in terms of the proportion of people who die from cancer is improving relative to other comparable countries. England now compares favourably with many other countries for mortality among men, for example France, Spain and Germany, although not so well for women. These results partly reflect the position of different countries on the curve of increasing and decreasing smoking incidence and hence on the curve of rising and falling incidence of lung and other cancers.
  - 15 In the past, England's survival rates were lower than for most other European countries and the United States. However, the most recent data available on an internationally comparable basis covers patients diagnosed in the early 1990s and whose 5-year survival pre-dates the changes introduced to English cancer services in recent years. There are limitations on the ability to make comparisons at a national level because cancer registries in many countries do not provide enough geographical coverage for direct comparison.

## Good practice is being introduced to build further on improvements in outcomes in the 1990s, but progress varies by cancer and locality

- 16 The NHS has concentrated on cancer prevention measures for behaviours which clearly increase the risk of cancer, such as tobacco consumption, but these measures will take time to have an impact. The NHS set up a national network of services in 2000 to help smokers give up. It is one part of the wider tobacco control strategy in the White Paper "Smoking Kills"<sup>ii</sup>. To date, the NHS Stop Smoking service, has helped about 340,000 people to quit at least temporarily (measured in numbers quitting for at least four weeks). We will comment in more detail on cancer prevention initiatives in our forthcoming study on the NHS Cancer Plan.

- 17** Screening women for breast cancer before symptoms are apparent has contributed to a sharp fall in mortality since its introduction in 1988. The programme now faces the challenge of extending its coverage while addressing low uptake in the London region. Clinical trials have established that screening for bowel cancer will significantly reduce mortality when it is introduced although it will inevitably add to pressure on resources for diagnosis and treatment. Unlike the breast (and cervical) screening programmes, screening for lung and prostate cancers has not yet been shown to reduce mortality with the techniques currently available, but research continues.
- 18** Some people do not seek immediate medical help when they develop symptoms that could point to cancer. There is little research on the reasons for, and impact of, patient delay, but a general lack of awareness of cancer symptoms continues to be a contributory factor in reducing survival. The NHS Cancer Plan acknowledged this as an area that needed to be addressed.
- 19** There is increasing evidence from cancer registries within England and across Europe that, at least for some cancers, people in England are diagnosed with cancer at a more advanced stage of development than in other European countries. This is likely to be due to a number of factors including patient delay in coming forward, difficulties for GPs in identifying symptoms early enough and waits for diagnostic tests within the hospital. How much each of these factors contributes to overall delays is not known. There is some evidence from individual cancer registries that within England, people in deprived areas are likely to be diagnosed with a more advanced stage of cancer than people from more affluent areas. The reasons for this are not known.
- 20** NHS Trusts have a target to ensure that patients referred urgently by General Practitioners (GPs) on suspicion of having cancer are seen by a specialist within two weeks of referral. However, GPs can have difficulty identifying those most at risk. GPs who responded to our survey gave us an indicative figure of approximately one third of patients they referred who were ultimately diagnosed with cancer but were not referred urgently and may therefore have had longer waits for assessment by a consultant. About half of the GPs we surveyed had seen the Department's referral guidelines and found them useful. Information flows between GPs and consultants are not always used as a way of improving the accuracy of referral, urgent or otherwise.
- 21** Measures are being introduced to address delays for patients awaiting diagnosis for possible cancer. Suspected cancer patients are major users of endoscopy, pathology and radiology services. Waits for endoscopies can be too long, following substantial increases in demand in recent years. Pathology services also suffer from shortages of trained staff and increasing demand. The NHS is greatly expanding its training capacity for endoscopists and pathologists and pilot projects are increasing speed of diagnosis by re-designing both services.



- 22** In some areas there are still long waits for diagnosis through radiological procedures such as CT and MRI scans or barium meals, partly due to shortages of skilled staff and large increases in demand for radiological procedures from non-cancer services. The NHS is improving services through a large-scale scanner replacement and renewal programme, increasing radiographer and radiologist numbers and innovative approaches to service redesign which have reduced waiting times considerably at pilot sites.
- 23** Dissemination of improving outcomes guidance (IOG) reports for specific cancers or groups of cancers started in the mid-1990s. The guidance reports emphasise that multi-disciplinary team (MDT) working and specialisation of complex cancer operations will improve outcomes for cancer patients. MDT working is now increasingly well embedded in the NHS but is demanding on staff time. Reconfiguration of some cancer services is already underway to enable specialisation in some complex procedures or cancers. However, IOG is at varying stages of implementation.
- 24** Waiting times for radiotherapy treatment can be too long, leading to courses of treatment not being delivered within good-practice times as specified by the Joint Council for Clinical Oncology. Delays are primarily due to a combination of lack of trained therapy radiographers (a worldwide shortage) and lack of linear accelerator capacity to deliver treatments. The Department of Health is seeking to address both issues through initiatives to recruit additional staff, increasing training places at universities (these have more than doubled between 1997 and 2002), introducing a new career structure for radiographers and procuring additional linear accelerators. There are also widespread initiatives to redesign local services for faster patient flows.
- 25** Large local variations in the availability of chemotherapy and other systemic therapies across England have been reported by pharmaceutical companies. The Secretary of State for Health has asked the National Cancer Director to investigate the variation in availability of cancer drugs approved by the National Institute for Clinical Excellence.
- 26** Treatment for similar cancer conditions can vary according to area and age between different groups (for example affluent versus deprived groups and younger versus older patient groups). There are some good reasons for this. For example, older people and those living in deprived areas may be less physically able to withstand radical treatments because of other co-existing illnesses. Variations in treatment may also, however, reflect lack of knowledge about treatment choices and some research has raised concerns that treatment decisions may not be made on all occasions on purely clinical grounds. The National Service Framework for Older People, published in 2001, recognises this. Unfortunately the data currently available do not permit a satisfactory analysis of these issues.

# Recommendations

- (a) Reducing tobacco use can make a major contribution to prevention of cancer. Not enough is currently known about the long-term effectiveness of NHS Stop Smoking services. The evaluation begun by the NHS to verify whether those who quit smoking through the services have managed to remain non-smokers should be completed and published, and the NHS must then act promptly on the conclusions. In addition, referral rates to stop smoking services and number of patients quitting for at least 4 weeks vary substantially between Strategic Health Authorities. Strenuous efforts should be made to bring all services up to the level of the best.
- (b) Since there are lead times of several years to introduce screening programmes, the Department of Health should, following completion of its option appraisal of the best test available, move swiftly to finalise an implementation timetable including recruitment of staff and workforce expansion for the national roll-out of bowel cancer screening. Consideration needs to be given to prioritisation of geographical areas with the highest bowel cancer mortality.
- (c) More action is needed to tackle the delay on the part of some patients in England in coming forward for medical advice when they have suspicious symptoms. In line with the NHS Cancer Plan the Department (working with the NHS) should co-ordinate the establishment of pilots to work with groups which are consistently diagnosed with cancer at a more advanced stage, to understand why they delay seeking medical advice and to encourage them to come forward earlier with symptoms. The pilots should be designed to avoid unnecessary anxiety to the public or overburdening primary care services.
- (d) The difficulty of identifying cancer symptoms at an early stage presents a major challenge to GPs. The National Institute for Clinical Excellence (NICE) is currently revising the Department's guidelines for GPs on referring patients with suspected cancer. NICE and the Department should implement a strategy to ensure that the updated guidelines for GPs are widely disseminated and acted upon. In addition, the NHS (through cancer Networks NHS trusts and PCTs) should encourage stronger relationships between GPs and hospitals to work together to improve assessment through the continued development of standardised referral procedures and feedback on appropriateness of GP referrals.
- (e) Inevitably, given the real difficulties in making accurate diagnosis for some cancers and, even with better adoption of good practice in referring, a proportion of patients ultimately diagnosed with the disease will not initially be referred urgently by GPs. The Department's existing target to measure time from GP referral to assessment by a specialist, and time from referral to treatment, only covers patients deemed urgent by GPs. The Department should therefore develop a mechanism to audit the time taken for assessment and treatment of patients who are referred routinely and subsequently diagnosed with cancer. The Department should also work with the Cancer Services Collaborative Improvement Partnership to identify where in the patient pathway delays are occurring for these patients, to enable action to be taken to address these delays.

- (f) Given the shortage of radiotherapy and radiology staff, hospitals providing these services should compile information on the capacity and demand for services in their area in order to assess local need for extra staff and facilities, and to assess opportunities for service improvement. Cancer Networks should work closely with local Workforce Development Confederations to ensure adequate training places are available in each area. An overview of the position should be compiled nationally at regular intervals.
- (g) Information should be made available for the benefit of local communities to show service improvements intended to address poor cancer outcomes in their locality. Primary Care Trusts, in association with cancer Networks, should identify the best vehicle to communicate this information, possibly through annual reports or patient prospectuses.
- (h) Waiting times for radiotherapy treatment for cancer patients can be too long and should be monitored at the local level using standardised national measures as a basis for prioritising the need for additional resources. At a local level Primary Care Trusts, working collaboratively with cancer Networks, should take waiting times and capacity and demand analyses into account when commissioning radiotherapy services.
- (i) Multi-disciplinary team (MDT) working is a key development in improving outcomes for cancer patients. In order to work effectively, it is essential that MDTs have adequate administrative support but some lack this. Primary Care Trusts, working through cancer Networks, should set out how they intend to provide this support, and set a timetable for doing so.
- (j) Patients access to anti-cancer drugs still appears to depend on where they live. SHAs working collaboratively with their PCTs and Cancer Networks should act speedily on the findings of the National Cancer Director's review of take-up of cancer drugs approved by the National Institute for Clinical Excellence (NICE) to make sure that patients in all areas have equal access to these cancer treatments.
- (k) It is currently very difficult to assess whether providers of cancer services deliver the best treatment to all age-groups of cancer patients. High priority should be given to implementation of the four national cancer clinical audits that sit within the National Clinical Audit Support Programme, which will allow this issue to be examined in depth. Clinical audits of this kind should be extended to all other major cancers as soon as possible.

## EXECUTIVE SUMMARY

### Tackling cancer: Improving the Patient Journey



**1** In July 2000, the NHS Plan made it clear that health services were to be designed around the patient. In September of the same year, in his Foreword to the Department's Cancer Plan, the Secretary of State for Health said of the Plan that, "perhaps most important of all, it puts the patient at the centre of cancer care".<sup>1</sup> One of the four main aims of the NHS Cancer Plan was "to ensure people with cancer get the right professional support and care as well as the best treatments".

**2** In 1999-2000 the Department of Health undertook a large scale national survey of cancer patients involving all NHS Trusts in England and covering six different types of cancer, to which over 65,000 cancer patients responded. That survey, published in 2002, provided a baseline to establish patients' experiences and opinions of the quality of service received in the period immediately before the implementation of the Cancer Plan. The survey found generally high levels of patient satisfaction in terms of issues such as dignity, privacy and respect, though it also identified areas for improvement.

**3** Since that survey, substantial additional funding has been provided for cancer services. The NHS Improvement Plan in June 2004 emphasised that the NHS is to be "not just a national health service but also a personal health service for every patient".<sup>2</sup> The Department of Health and the NHS have introduced a range of measures to improve access, and good practice guidance has been set out to govern what needs to be done to make the patient experience as acceptable as possible.<sup>3</sup> Most recently, the National Institute for Clinical Excellence issued guidance on improving supportive and palliative care in March 2004, though there has not been sufficient time for this to impact on the findings of this report.

**4** We therefore carried out a national follow up survey of patients with the cancers that cause the most deaths, to gauge progress made in the four years since the introduction of the Cancer Plan. The survey was carried out in the early months of 2004 and involved responses from patients in 49 NHS Trusts with the four commonest cancers: breast, lung, bowel and prostate cancer. Between them, these cancers account for some 115,000 new cases each year. Some 7,800 patients were invited to participate in our survey, of whom 4,300 responded (55 per cent). The work is a companion to our two other reports on cancer services.<sup>4</sup> We also visited hospitals and hospices to talk to clinical staff involved in cancer services and held focus groups and one-to-one interviews with GPs, nurses, patients and carers.

**5** We also asked a small number of people with cancer, who volunteered, to talk about their experiences. These are recorded on the video disks attached to this report. The commentaries relate to the issues of interest in this report, and are intended to provide additional insight about what it is like to have cancer, over and above the statistical analysis in the report. The views expressed are those of the speakers and are not a part of the formal audit findings of this report.

**6** Overall, we found encouraging progress had been made in most aspects of the patient experience, though for a minority of patients, elements of the patient experience were still not as good as they might be, such as communicating information, symptom relief and the lack of options for some patients in their last days. Prostate cancer patients continued to have a worse experience than those with other cancers and patients' experience of services in London remained less positive than elsewhere in England, even after taking into account other factors which could influence the patient experience.

**7** The table overleaf provides an overview of the changes in patients' views since 2000, for questions identified as representative of the main themes within the national surveys of cancer patients.

<sup>1</sup> The NHS Cancer Plan, *A Plan for Investment: A Plan for Reform*, Department of Health (2000).

<sup>2</sup> Foreword by the Prime Minister, *The NHS Improvement Plan*, HM Government.

<sup>3</sup> See National Audit Office Reports, *Tackling Cancer: Saving More Lives*, HC 364, Session 2003-04; and *The NHS Cancer Plan*, HC 343, Session 2004-05.

<sup>4</sup> See National Audit Office Reports, *Tackling Cancer: Saving More Lives*, HC 364, Session 2003-04; and *The NHS Cancer Plan*, HC 343, Session 2004-05.

**Key items from surveys of cancer patients' experience of treatment and care: comparison between 2000 and 2004**

	2000 %	2004 %
Patients did not perceive a worsening in their condition while waiting to see specialist	74	80
Patients told what was wrong with them with sufficient sensitivity and care (n/s)	94	94
Doctors or nurses discussed the purpose of treatment with patients, and patients completely understood the explanation	82	86
Patients found doctors' explanation of condition, treatment or tests very easy to understand	62	68
Patient always had trust and confidence in nurses	79	81
Patients with strong religious beliefs felt beliefs were taken into consideration by hospital staff	*	91
Printed information given to patient at discharge covered all the issues	*	96
Patient told about support or self-help group (n/s)	61	60
Patient had enough privacy during their examination at their last outpatient visit	99	97
A lot of confidence and trust in the doctor at the last outpatient appointment	68	84

## NOTES

- 1 Items are drawn from representative questions for each "theme" within the 2004 NAO Cancer Patient Survey (see Appendix 2).
- 2 For the items marked (n/s) the year-on-year change is not statistically significant.
- 3 Questions marked \* not asked in 2000.

## Cancer patients were broadly positive about their experience with GPs, the speed of diagnosis and how they were informed they have cancer

**8** The experience of care of more than four in five patients in 2004 was positive prior to diagnosis and two thirds of patients stated that care received from their GP was "very good". Fifty eight per cent of patients were seen by a specialist within two weeks of referral from their GP compared with 46 per cent in 2000. The proportion of patients perceiving their condition as worsening during the wait fell from over a quarter in 2000 to a fifth in 2004. Patients referred urgently by their GP are now seen almost universally by a specialist within two weeks, but a significant minority of patients diagnosed with cancer are not referred urgently.

**9** More than nine in ten patients considered they were told bad news with suitable sensitivity and more verbal and written information about diagnosis of cancer was communicated to patients, with greater success and sensitivity, than in 2000. Similar proportions understood the explanation given by clinicians of what was wrong with them and approved of the length of consultations. In future, more patients will be given a record to consider after the consultation. Patients who received printed information about their diagnosis were happy with it, and it was provided more often than in 2000. Nevertheless, four in ten cancer patients did not receive it. Patients without English as a first language have particular problems with receiving suitable information.

## Cancer patients' experience of care given by hospitals improved since 2000 but there are still gaps in supportive and palliative care

**10** Patients and their carers were more involved in care and treatment decisions than in 2000, and patients reported better communication about their condition, treatments and tests, although older patients and those with prostate cancer reported less positive experiences. Understanding of side effects improved significantly after 2000, but one quarter of patients said they either had less than a full understanding, or the issue was not discussed with them.

**11** Discussions with patients about how treatment had gone were seen as broadly satisfactory, but a fifth of patients reported that their understanding had not been complete. Most patients were not told how to complain and some had difficulty in getting a satisfactory result when they did so, particularly breast cancer patients.

**12** Almost all patients reported receiving sufficient respect, privacy and dignity during their hospital stay in 2004, though there remained concerns for a small minority around respect and dignity and privacy during discussions with hospital staff about their condition. Most patients felt they were treated respectfully and sensitively but the means of accessing religious support was not clear to a number of patients.

**13** Patients largely gave positive responses regarding the nature of the care they received from hospital doctors and nurses. More than four in five patients visiting hospital thought there are always enough doctors and nurses on duty (about five per cent more than in 2000) although more could have been done to ensure patients had named nurses. Outpatients spent more time with doctors and nurses than in 2000, but appointments still rarely ran to time. More than four in five patients undergoing first treatment had trust in the doctors and nurses who cared for them. Trust and confidence in the doctor seen at the most recent outpatient visit was at a similar level, a marked improvement over the position in 2000.

**14** More than nine patients in ten thought that hospital staff had done all they could to ease pain, although this was less likely among patients who had to tell staff about their pain, rather than have their pain level assessed by staff. A large majority of patients stated that they received support in dealing with distress and anxiety when needed, but a fifth of those in hospital and a quarter of those outside hospital who felt they needed help did not receive it. Patients who used them were enthusiastic for what they perceived as the benefits offered by complementary therapy services, but the extent to which they were informed about such services did not meet recent good practice guidance.

## Most cancer patients were content with the support they received after discharge and as outpatients, but hospice provision and end of life choices could be enhanced

**15** A large majority of cancer patients received information about what will happen after hospital. A fifth of patients reported that they did not receive printed information, and for a fifth of patients, home circumstances were not fully taken into account in arranging discharge. Most patients were well informed and knew what to expect when leaving hospital. Patients were satisfied with the information provided they received it.

**16** After leaving hospital, three quarters of patients got the help they needed from the NHS and thought it met patients' needs very well. Pain relief after leaving hospital generally met patients' needs but patients frequently experienced overwhelming tiredness and 12 per cent of patients experienced this while reporting that not enough was done to alleviate it. Most patients lacked access to advice about financial benefits to support them or their family during or after their illness, though many wanted it while information about support groups continued to be received by around 60 per cent of patients.

**17** The Department of Health is substantially increasing funding for the development of specialist palliative care services to be delivered by multi-disciplinary teams in the community, but coverage by multi-disciplinary teams in the community is not even across regions of England. Hospices, while welcoming recent initiatives, felt that staff and other resources remain constraints and a wider range of services should be provided.

**18** Many terminally ill cancer patients have strong preferences about how they wish to spend their final days. Research shows that cancer patients often do not die in their place of choice.

**The patient experience differed across cancer types and English regions**

**19** Within the overall results of our survey, we found noticeable and statistically significant differences between some groups of cancer patients after adjusting for possible other influences:

**Cancer types**

**20** Responses from patients with breast and prostate cancers were more likely to differ from other cancers in survey responses to particular questions. Breast cancer patients were more positive than others in respect of the provision of information at diagnosis and on discharge from hospital, and in the rapidity of referral from GP to specialist where only three out of ten patients waited more than two weeks.

**21** In the NAO survey, after excluding purely factual questions, we looked at the remaining 80 questions which made judgements about the quality of care provided. Patients with prostate cancer gave less positive responses than patients with other cancer types for 54 of these questions, and gave the most positive response to only 8 of the questions. Differences were particularly noticeable in the survey responses shown in **Figure 1**. These variations were also seen in 2000. Since 2000 the percentage of positive responses has generally improved for all cancers but more strongly for cancers other than prostate, leading in some areas of the patient experience to a widening gap in responses between patients with prostate cancer and those with other cancers.

**22** More detailed statistical analysis strongly suggests that negative experiences of prostate patients persist even after allowing for regional, gender and age effects. The National Institute for Clinical Excellence issued Improving Outcomes Guidance on urological cancers in 2002, later than for other major cancers. The Department told us that this may explain partly why responses from prostate cancer patients are less positive.

	2000 %		2004 %	
	Patients with prostate cancer	Patients with other cancers	Patients with prostate cancer	Patients with other cancers
Waited more than two weeks from referral by GP to be seen by specialist	72	49	68	37
Not discussed the side effects of treatment	19	15	11	6
Not discussed how treatment had gone	14	8	13	5
Would have preferred more information about how treatment had gone	21	18	20	13
Fully understood explanation of how treatment had gone	67	76	70	81
Have a named nurse in charge of care	43	56	50	61
Home situation not taken into account when discharged from hospital	21	14	13	9
Given information about support or self-help groups	36	66	34	64
Outpatient appointment cancelled one or more times	17	13	19	11



## Geographical variations

**23** Our geographical analysis was based on the boundaries of the four Regional Directorates of Health and Social Care: London, the South, the Midlands and East, and the North. At this high level, differences are statistically significant. Taking the 80 questions referred to in paragraph 21, patients from the London region gave less positive responses than patients from other regions for 62 of these questions, and gave the most positive response to only eight of the questions. Differences were particularly noticeable in a range of survey questions in relation to Community and Hospital services, and the interface between them. Further analysis strongly indicates that the less positive experience of London cancer patients in these questions persists even after allowing for cancer type, gender and age differences.

**24** Although London patients recorded a less positive qualitative experience of care, our previous report, *Tackling Cancer: Saving More Lives*,<sup>5</sup> did not show that cancer patients in London have worse survival and mortality rates than other parts of England.

## Black and minority ethnic groups

**25** Our survey had limited representation of black and minority ethnic patients, with only some 120 respondents (2.8 per cent of all respondents – roughly the same as in the 2000 survey). Around half of these respondents did not have English as a first language, which limited our ability to make observations in this area. However, black and minority ethnic groups have been shown by past research to have particular difficulties as cancer patients (and in dealings with the NHS generally). Reduced cultural sensitivity – such as provision for religious beliefs – and communications issues are more prevalent for minority ethnic cancer patients, who were less likely to understand their diagnosis and treatment options. Black and minority ethnic groups are less likely to be referred to, or choose to go to, hospice cancer services than other groups in society.

## Deprivation

**26** We divided the respondents to our survey into four groups of patients (using their postcode), from deprived to affluent, using the Index of Multiple Deprivation. Differences between the groups were very small for almost every question in the survey and there was no consistent statistically significant pattern of the most deprived group having more negative responses to survey questions than other groups. In other words they did not have a more negative perception of the service that they received from the NHS than more affluent patients.

## Adverse experiences

**27** We looked to see if the more negative experiences were concentrated within a particular group of patients. We focused on the eight questions where our survey showed that approximately one fifth of respondents had given less positive responses. This was to see if negative responses were the result of a particular group of patients registering across-the-board negative responses. The results indicate that this is not the case. Only two respondents gave a negative response to all eight questions. However, some groups were over-represented among those giving multiple negative responses: patients from London, and those with prostate and bowel cancer.

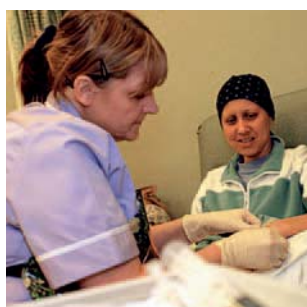


**a** Many of the ways of achieving the improvements to enhance the patient experience are already set out in guidance from the National Institute for Clinical Excellence. Cancer Networks have recently developed action plans to implement the guidance – Strategic Health Authorities (SHAs) should confirm that these action plans will deliver the necessary improvements over the next three years. The Cancer Action Team should collate information from all 34 Network action plans to assess the extent to which the guidance will be fully implemented within the next three years. Comparative information should be fed back to networks and SHAs.

**b** User involvement in cancer services is supported by Partnership Groups (a forum for bringing together health professionals and service users), reflecting good practice guidance from the National Institute for Clinical Excellence and the Manual of Cancer Services. SHAs should satisfy themselves through the performance management of Cancer Network action plans that these Partnership Groups are adequately resourced.

**c** Regular good quality surveys of patient experience should be undertaken at a local level to help drive up the quality of care. The questionnaire developed for the National Cancer Patient Survey and used with amendments in the current NAO study, should be adapted as a template, and piloted for use on a regular basis by Cancer Networks, NHS Trusts and individual cancer teams. This will avoid duplication of effort and provide consistency across areas for comparability purposes. Issues identified as weaknesses should be surveyed using more detailed modules of the full survey. The findings of such assessments should inform commissioning.

**d** Prostate cancer patients in the survey conducted for this study reported a generally poorer experience of care than patients with other common cancers. Particular attention should therefore be given by Cancer Networks to implementing the guidance on urological cancers, of which prostate cancer is one, not least by providing all patients with access to a urological cancer nurse specialist, in a way that is measurable and allows for comparisons with other areas.



**e** The worse experience of care reported by patients in London should be investigated further. The National Cancer Director should ensure that the Strategic Health Authorities and Cancer Networks in London are aware of this and that appropriate remedial action is taken.

**f** The work undertaken through the Cancer Services Collaborative 'Improvement Partnership' to develop Network-wide approaches to information delivery should be extended to all Cancer Networks and all tumour types as soon as is reasonably possible.

**g** The advanced communication skills programme currently being developed by the Cancer Action Team and the NHSU (the corporate university for the NHS), intended to improve communication between health professionals and cancer patients, their families and carers, should be rolled out to healthcare professionals across England as soon as possible.

**h** The Cancer Action Team should develop a standardised approach to the assessment of patients' physical, psychological, social and spiritual needs for use by all health professionals caring for patients with cancer. Services to meet patients' needs should be established in line with NICE guidance.

## EXECUTIVE SUMMARY

### The NHS Cancer Plan: A Progress Report



**1** This is the final report in a series of three National Audit Office studies on cancer services in England. The first<sup>1</sup> examined whether clinical aspects of cancer services are saving more lives across England and in comparison to other countries. The second study<sup>2</sup> examines how patients view services, based on the results of a major survey of cancer patients. This report focuses on the NHS Cancer Plan, reviewing its content, examining its implementation across the country, and reporting on progress to date against the targets and commitments in the Plan.

**2** The NHS Cancer Plan was published in September 2000 and built on commitments set out in the NHS Plan, published two months earlier, which promised more staff and equipment for cancer along with a modernised NHS, with new ways of working to prevent and treat cancer. The NHS Cancer Plan is a ten-year programme of fundamental reform of cancer services in England. It formally established cancer networks across the country, bringing together the organisations and health professionals which plan and deliver treatment and care for cancer patients. The aims of the NHS Cancer Plan are:

- to save more lives;
- to ensure people with cancer get the right professional support and care as well as the best treatment;
- to tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals; and
- to build for the future through investment in the cancer workforce, through strong research and thorough preparation for the genetics revolution, so that the NHS never falls behind in cancer again.

**3** The main participants in the implementation of the Plan are shown in **Figure 1**.

**4** It will take time for the effects of the Plan to work through fully. To evaluate its impact to date we drew on a survey of all cancer networks, discussions with a wide range of health professionals within cancer networks across the country, a review of Department of Health papers and other material, and the advice of a panel of experts to provide a progress report on the NHS Cancer Plan some four years into its ten-year programme.

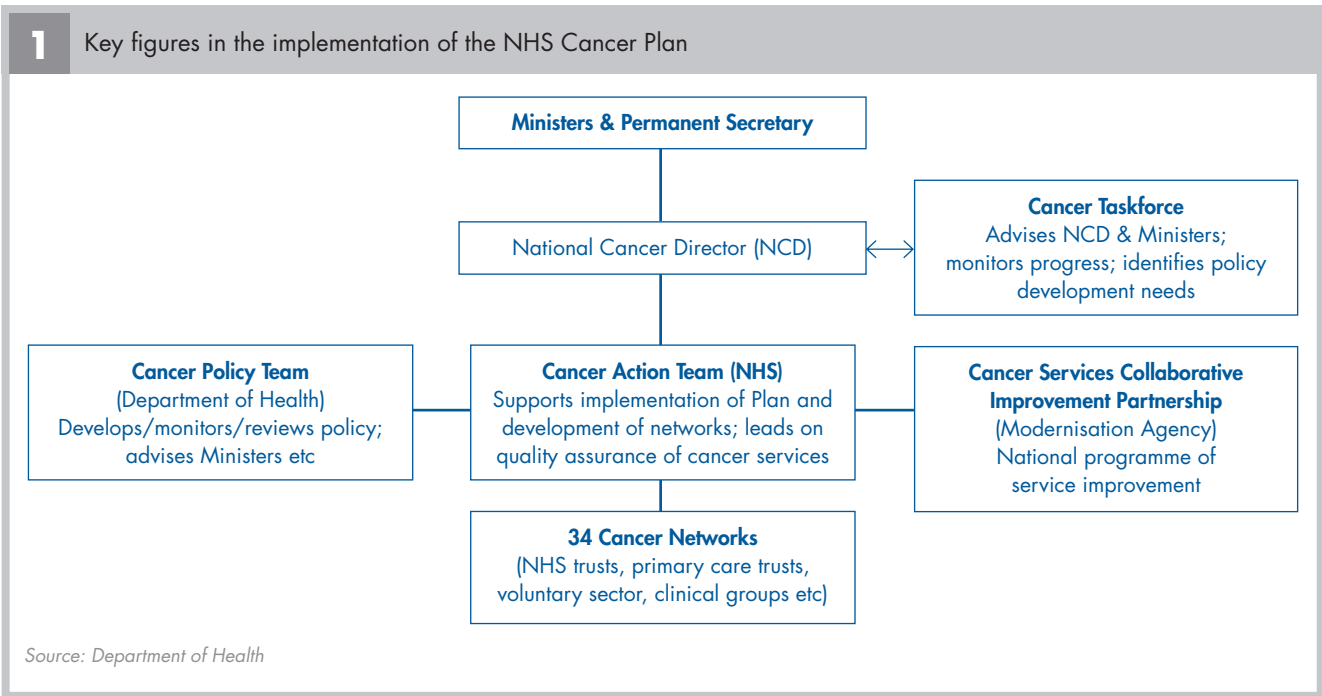
**5** Overall, we found that:

- the Plan was generally well conceived and substantial progress has been made to date, with many targets in the Plan met or on course to be met. This should contribute to the downward trend in mortality rates observed for England, which are ahead of the Department's trajectory to achieve the target of a 20 per cent reduction in mortality from cancer in persons under 75 by 2010;
- while cancer networks – the vehicle for securing improvements in local cancer services – have made progress with some significant successes, they are not always as effective as they could be in terms of staffing, cancer services planning or in receiving the full support of other parts of the healthcare system. Networks were established before primary care trusts and other NHS organisational changes, and there is scope for working arrangements to evolve further.

We make a number of recommendations to consolidate progress to date and to reinforce networks and partnership working.

<sup>1</sup> 'Tackling cancer in England: saving more lives'. (HC 364, 2003-04). Published March 2004.

<sup>2</sup> 'Tackling Cancer: Improving the Patient Journey'. (HC 288, 2004-05). Published February 2005.



## The NHS Cancer Plan is broadly comprehensive but strategy will need to be kept up to date

**6** We found that the NHS Cancer Plan is impressive in its coverage of the main elements of World Health Organisation guidelines<sup>3</sup> (especially as they were published after the NHS Cancer Plan) for designing strategies against cancer, effectively setting out a series of targets, commitments and milestones for improving cancer services. The Plan compares favourably with other national and state cancer plans published in recent years, and is regarded by cancer networks as a useful tool outlining strategic direction across the patient pathway.

**7** However there are ways in which the strategy for tackling cancer in England could be improved to cover, for example, strategic issues such as estimates of the future cancer burden. Decisions now need to be taken on how to update and bring together all elements of the current cancer strategy in a unified way that ensures that it remains the central guiding approach for improving cancer services and outcomes.

## The Plan has resulted in improvements to cancer services though there is still more to be done

**8** The 34 cancer networks in England are responsible for implementing the NHS Cancer Plan. Almost all cancer network organisations we spoke to were positive about progress against the NHS Cancer Plan, partly because of the initiatives to identify and spread good practice put in place by the Department of Health and the Cancer Action Team, which supports implementation of the Plan within the NHS.

<sup>3</sup> National Cancer Control Programmes: Policies and Managerial Guidelines. WHO, 2002.

**9** The NHS Cancer Plan contains a very significant number of targets and commitments to be achieved during its ten-year lifetime. Progress to date in meeting them has been encouraging, including:

- Boosting the downward trend in smoking;
- Extending the breast screening programme;
- Speeding access to cancer diagnosis and treatment;
- Establishing specialist cancer teams;
- Reducing variation in access to cancer drugs;
- Boosting specialist palliative care services;
- Getting more cancer specialists in place, and faster than planned;
- Modernising and expanding cancer diagnostic and treatment facilities; and
- Increasing the pace of research.

**10** Overall, though there has been some slippage in meeting some NHS Cancer Plan target dates, much has been achieved, and major improvements in cancer services secured. But some targets, such as achieving the waiting time targets for 2005, pose significant challenges if they are to be fully met.

**11** In addition to the NHS Cancer Plan the Department has launched a number of related initiatives to improve cancer services, including a tobacco advertising ban, establishing an integrated cancer care programme to improve coordination of care, and strengthening the partnership between the NHS and the voluntary sector.

## Cancer networks have helped drive forward improvements in cancer services, but there is more to do if they are all to become fully effective

**12** Most cancer patients require care from many parts of the NHS at different points in their care journey. Primary, secondary and tertiary care, as well as the voluntary sector (such as hospices), need to work closely together to provide an integrated system of care. Cancer networks were set up to achieve integrated care as well as improved clinical outcomes, cost-effective services, improved patient experience and equity of service provision.

**13** The NHS Cancer Plan established cancer networks as the vehicle for the delivery of cancer care. The first wave of cancer networks was established following the recommendations of the Calman Hine report, published in 1995. As a result of the NHS Cancer Plan full coverage in England was achieved, with a total of 34 networks established. The networks are responsible for developing and planning all aspects of cancer services. They are matrix organisations, combining expertise and input mainly from acute and primary care trusts, the voluntary sector, numerous generic and tumour-specific working groups, and a patient and user group, coordinated by a network management team and headed by a network board.

**14** Cancer networks have, in a short time, helped to improve cancer services in England; though some have achieved more than others reflecting, in part, their current state of development. In terms of particular successes, cancer networks have, for example:

- planned for the introduction of new cancer drugs across the network;
- developed plans for funding specialist palliative care;
- drawn up action plans for the development of cancer services in line with guidance from the National Institute for Clinical Excellence; and
- facilitated development of multidisciplinary teams, which are an important element in delivering improved patient-centred treatment and better outcomes.

**15** The extent to which networks have been fully established, and the degree therefore to which they are fully effective varies, however, and there is more to be done if all 34 networks are to function as effectively as possible. Important issues are:

- **Sufficient resources are not always available to enable networks to operate effectively.** We found that not all network management teams were fully staffed, with some networks having vacancies for essential posts. The staffing of additional desirable posts was also a challenge, with financial constraints given as the main explanation. Funding overall was seen as a problem by some networks.
- **Making the cross-boundary approach work has not been straightforward.** We found that some network boards did not have full representation from acute and primary care trusts in their area. Where present, representation was only at the expected Chief Executive level in around half of cases.
- **Not all cancer networks plan effectively.** Networks were required to prepare three-year service delivery plans by 2001, underpinned by workforce, and education and training strategies. Three of the ten networks we spoke to did not have a current service delivery plan, and although at a national level workforce development was seen as a priority in the NHS Cancer Plan, by late 2003 only a third of networks had produced a workforce strategy; and just over a third had developed an education and training strategy.
- **There is scope to improve the commissioning of cancer services in some networks.** Some primary care trust commissioners produce plans for cancer service provision in isolation, when they should be cooperating with other network constituent organisations. The extent to which network management teams input to the commissioning process also varies.
- **There are concerns regarding the duty of partnership expected from cancer network organisations in the context of an evolving NHS.** Generally, network management teams reported effective relationships between the networks and their constituent organisations, particularly in the case of acute trusts. However at the more strategic level some strategic health authorities were very proactive, whilst others made no reference to the cancer network in their summary local development plans. Some networks expressed concerns that, while NHS foundation trusts have the scope to benefit cancer patients, the freedoms that they have may limit effective partnership working and collective efficiency. Similar risks may arise with the emergence of independent sector treatment centres.





## RECOMMENDATIONS

- 1** The NHS Cancer Plan is a good model from which other countries have taken inspiration. The National Cancer Director should continue to work with his equivalents overseas to share good practice in drawing up and implementing blueprints for the development of cancer services, taking account of good practice abroad that would be applicable in England.
- 2** With the approach of the mid-point in the ten-year life of the Plan, the National Cancer Director should - taking account of the changed and changing environment of the NHS, subsequent guidance published by the Department to take the Plan forward, and the views of stakeholders – consider what changes to the cancer strategy are needed, and how these should most appropriately be brought together and published in a unified and accessible form.
- 3** As part of its corporate accountability, the Department of Health should continue to publish progress against the key cancer outcomes in Figure 8 of this report as part of its existing reporting mechanisms.
- 4** Cancer networks should ensure that they are able to demonstrate to strategic health authorities that they have appropriate planning arrangements in place locally, including workforce and education and training strategies, and that these feed into the Local Delivery Plan process.
- 5** Strategic health authorities, working through primary care trusts, need to ensure that networks have the resources required for an effective and sustainable performance.
- 6** All networks should have agreed arrangements in place with local partners for monitoring progress against those targets for which they are responsible, and implement them. Where that is deemed not to be the case, the strategic health authority should take corrective action.
- 7** The network board should send annually updated information to its constituent bodies and its strategic health authority, to update them on progress against the NHS Cancer Plan. This information should be copied for information to the National Cancer Director so that he can have an overview of progress. Any performance management response needed would be for the strategic health authority to take forward.
- 8** To make cancer networks work better as cross-boundary organisations the Department of Health, in association with strategic health authorities, should strengthen the functioning of cancer networks by ensuring that roles and responsibilities of constituent organisations are clearly defined and adhered to. The outputs from this process should include clear common stated aims, to which all bodies should subscribe, with associated responsibilities and accountabilities.