

### Tackling cancer in England: saving more lives

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL HC 364 Session 2003-2004: 19 March 2004



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John Bourn Comptroller and Auditor General National Audit Office 15 March 2004

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## 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. Those involved in delivering improvements are shown at Appendix 1, including 34 Cancer Networks responsible for delivering the Cancer Plan at a local level.
- 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 is it 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. Our methodology is shown at Appendix 2.

## 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>i</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;

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.

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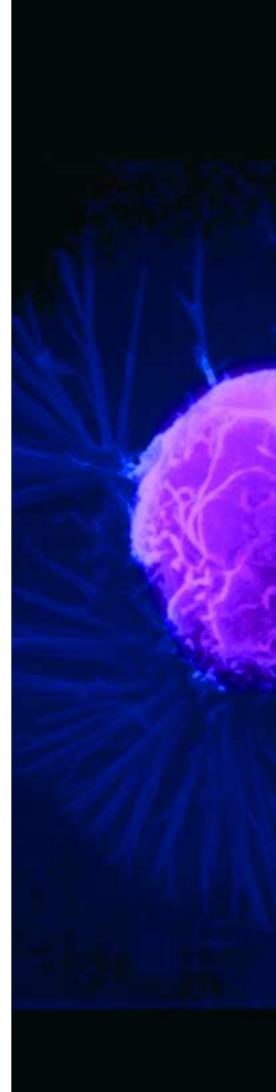
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- Bowel cancer. Incidence rates have risen very slowly for two decades, while mortality rates have fallen by over 25 per cent. 5-year survival rates have risen steadily to nearly 50 per cent; and
- Prostate cancer. The introduction of the Prostate 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 effectives 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.







# Part 1

Cancer survival and mortality rates are improving in England despite increasing incidence of cancer

### Since 1971 cancer incidence in England has increased, mortality has fallen and survival has improved

Key measures of progress in tackling cancer are rates of incidence, mortality and survival

- 1.1 Comparative analysis of cancer trends usually centres on incidence, mortality and cancer survival within defined populations<sup>iii</sup>. Each has a role in measuring success in the battle against cancer as follows:
  - Incidence rates (the number of new cancer cases that occur per 100,000 in the population) give indications of the success in preventing cancer. The best way to deal with the disease is to stop it occurring in the first place;
  - Mortality rates (the number of deaths from cancer per 100,000 in the population) are important for showing how many people are dying from the disease. These rates reflect a combination of the incidence of cancer, how advanced the disease is at the time of diagnosis and the effectiveness of treatment. Rates are "age-standardised" to allow for differing age structures among populations, either to a European (E) or a World (W) standard population;
  - Survival rates (based on measures of the percentage of those diagnosed with cancer who are still alive five years after diagnosis) are important for providing a picture of how advanced cancer is in patients at time of diagnosis and how effectively they are treated. A five-year period is the internationally accepted standard measure of survival. Survival is often expressed in terms of "relative survival". This is the ratio of the observed survival rates in the population studied compared to the survival rates expected in the population in the absence of cancer. Relative survival rates are slightly higher than crude survival rates. We have used relative survival rates in this report.

The overall incidence rate of cancer has increased and mortality rates fallen

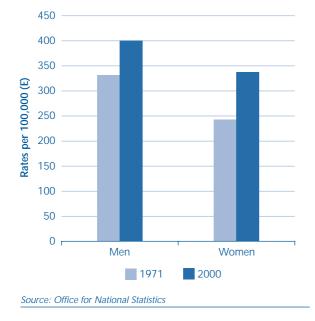
- 1.2 Figures 1 and 2 show the changes in cancer incidence and mortality rates in England during the past three decades. Between 1971 and 2000 cancer incidence overall increased by 31 per cent (21 per cent for men and 39 per cent for women). Between 1971 and 2002 cancer mortality overall fell by 12 per cent (18 per cent for men and 7 per cent for women). Figure 3 shows the trends in incidence and mortality between 1971 and 2000-02 in England.
- 1.3 Mortality from cancer varies widely within England. In 1998-2000 the overall mortality rate for people under 75 years was 130 per 100,000. For the 95 district health authorities in existence at that time mortality rates ranged from 101 to 193 per 100,000 - high mortality rates being observed in districts with higher levels of deprivation. In large part this relates to differences in incidence and mortality for lung cancer. Reductions in mortality between 1995-1997 and 1998-2000 were observed in almost all of the old district health authorities. However progress was not uniform with much larger improvements in some districts than others. Variations in the level of improvement were not obviously linked to levels of affluence and deprivation.

Five-year survival rates for cancer have also increased

1.4 **Figure 4** shows improvements in 5 year relative survival rates for all cancers for men and women in England.

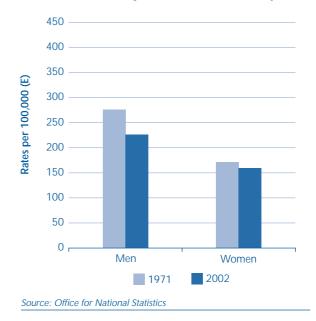


In women the increases have been most marked in breast and lung cancer. Reported increases in incidence are partly due to improved data collection since the 1970s.



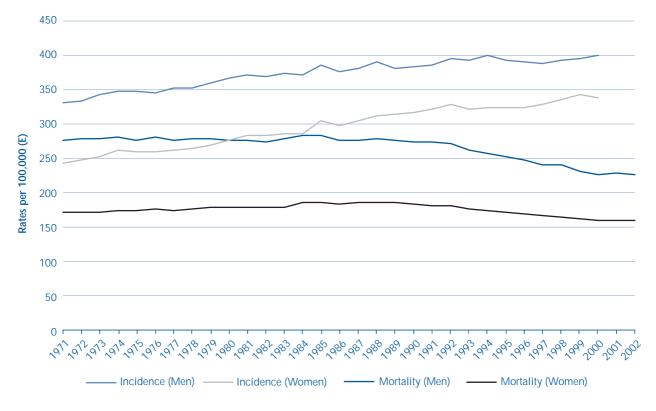


The decline in smoking-related cancers has reduced mortality in men. This has not happened so far for women, although women have benefited from a large fall in breast cancer mortality.



### Increasing incidence and declining mortality over time in England (all cancers)

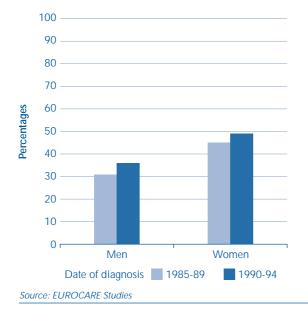
Although cancer incidence has risen steadily since the early 1970s, mortality is falling. For women, although incidence and mortality is lower than for men, incidence is increasing at a faster rate and mortality declining at a slower rate.



3

### Improvement in five-year relative survival in England (all cancers)

Five-year survival rates for men improved to 36 per cent for those diagnosed in the early 1990s, and to 49 per cent for women. The lower survival rates in men in both the periods reflect the larger number of men having cancers with poor survival chances, particularly lung cancer.



Deprivation<sup>2</sup> continues to have a major impact on survival rates

- 1.5 Although survival rates are increasing for all sectors of the population, recent research has shown that they are increasing faster for the affluent than for the deprived, creating a widening "survival gap" iv. The research found that the gap in survival between rich and poor was wider for those diagnosed during 1996-99 than for those diagnosed during 1986-90 for 12 of the 16 cancers examined in men and nine of the 17 cancers examined in women. Trends for the 4 commonest cancers are as follows:
  - The survival gap for breast cancer stayed constant during the 1990s with a difference of around 6 per cent between the most affluent and most deprived areas;
  - for lung cancer, the survival gap was less than 2 per cent for men and smaller still for women, with little change over time;
  - the survival gap for colon and rectal (bowel) cancers became significantly steeper for both sexes in the 1990s, to 7 per cent for colon cancer and 9 per cent for rectal cancer; and
  - for prostate cancer, the survival gap increased steeply during the 1990s to over 7 per cent.

### England is continuing to improve on past performance in tackling the four major cancers

1.6 The 4 commonest cancers - breast, lung, bowel (colon and rectal) and prostate cancer - account for just over half of the cancers diagnosed each year, and just under half of cancer deaths. Figure 5 gives the latest available data for the four cancers.

Breast cancer: survival and mortality rates are improving despite a significant rise in the level of incidence

- 1.7 Incidence rates for breast cancer rose 47 per cent between 1980 and 2000, chiefly among more affluent women<sup>v</sup>. Mortality rates were broadly constant up until 1989 and fell by more than 25 per cent between 1989 and 2002. (see Figure 6).
- 1.8 There have been great improvements in five-year breast cancer survival rates (see Figure 7). For women diagnosed between 1971 and 1975 the five-year relative survival rate was 52 per cent, rising to 78 per cent for those diagnosed between 1996 and 1999.

Lung cancer: There has been a sharp fall in incidence and mortality rates although survival rates are static

1.9 The pattern of lung cancer incidence and mortality rates over the past thirty years has been dictated by smoking prevalence (see Figure 8 overleaf). In addition, five-year survival rates have remained very low over time, at around 6 per cent for men and women, because the disease is already at an advanced stage by the time of diagnosis for the large majority of patients.

### 5 Numbers of cases and deaths from cancer in England (men and women)

|                          | Number of newly<br>registered cases 2000<br>(000) | Number of<br>deaths 2002<br>(000) |
|--------------------------|---|-----------------------------------|
| All cancers <sup>1</sup> | 224   | 128                               |
| Four commonest           |   |                                   |
| cancers:                 |   |                                   |
| Breast <sup>2</sup>      | 34  | 11                                |
| Lung                     | 31  | 27                                |
| Bowel                    | 28  | 13                                |
| Prostate                 | 23  | 8                                 |
| Sub-Total                | 116 (52 per cent)                                 | 59 (46 per cent)                  |

#### NOTES

- 1 Excluding non-melanoma skin cancers. The recorded incidence rates for these are very unreliable because they are frequently treated in the community.
- 2 Excludes male breast cancer (less than 70 deaths a year).

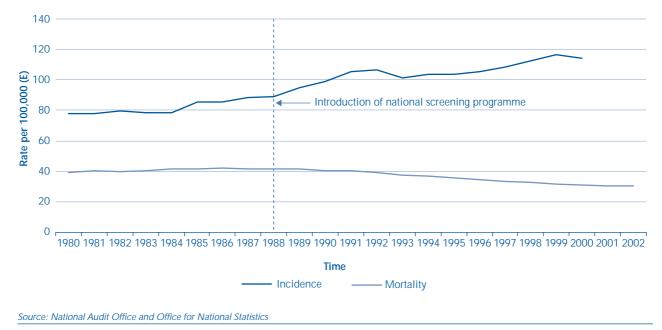
Source: National Audit Office, Office for National Statistics and National Centre for Health Outcomes Development

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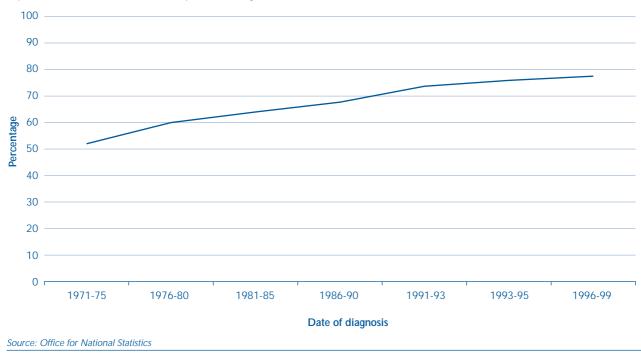
"Deprivation" is calculated by giving a rating to a patient's place of residence based on variables such as level of unemployment and car ownership from the 1991 census (Carstairs, Deprivation indices: Their interpretation and use in relation to health. Journal of Epidermiology and Community Health 1995: 49: S3-S8) or the level of income-deprivation as shown by receipt of benefits and income support in 1998 (Department of Environment, Transport and the Regions. Measuring multiple deprivation at the small area level: the indices of deprivation 2000). 6

### Increasing incidence and declining mortality for Breast Cancer from 1980 in England

Risk factors contributing to increases in incidence of breast cancer include increasing age of patient at birth of first child, increasing obesity and lack of physical activity, and increasing use of hormone replacement treatment. Falls in mortality rates are attributable to the more or less simultaneous introduction in the late 1980s of a national breast-screening programme (the largest falls have been in the age-group covered by the screening programme) and the introduction of hormone therapies and chemotherapy to reduce the risk of relapse.



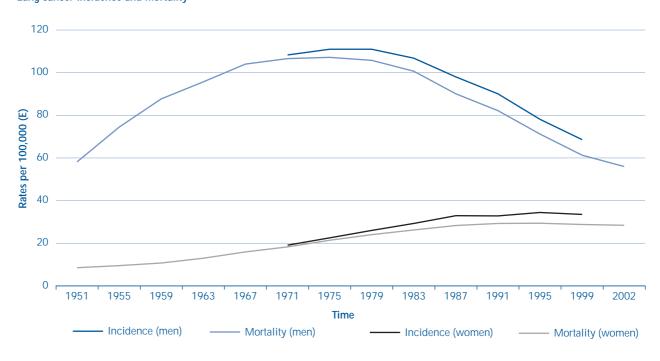
### Increase in five year relative survival rates for breast cancer



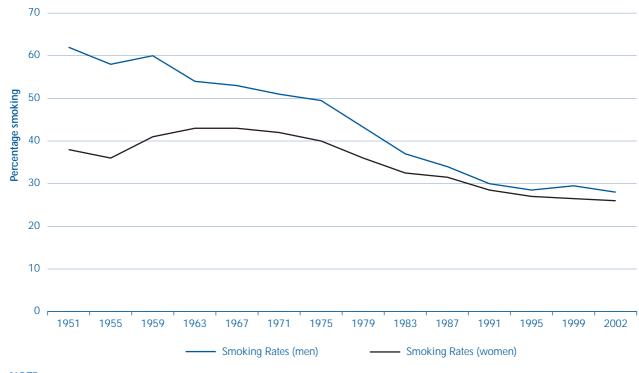
Improvements in survival reflect developments in early detection and treatment of breast cancer.

### 8 Lung cancer incidence and mortality rates for men and women reflect smoking patterns in earlier decades

In the first national survey in 1948, smoking rates for men stood at 82 per cent. As smoking reduced, incidence and mortality rates for men fell by 36 and 42 per cent respectively from their 1974 peak. For women, incidence has risen 76 per cent since 1971, while mortality has levelled out after peaking in the mid-1990s, reflecting the fact that smoking among women peaked as late as the 1960s.



#### Lung cancer incidence and mortality



Smoking rates

### NOTE

Incidence and mortality rates are for England and Wales, smoking rates are for whole of the UK.

9

Bowel cancer: mortality rates have been falling slowly for some time while survival rates have increased

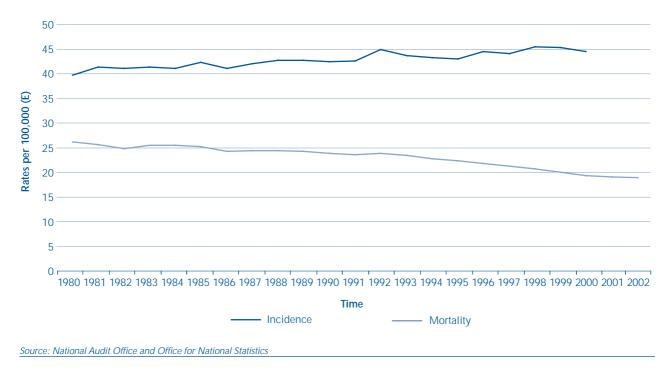
1.10 Incidence and mortality rates for bowel (colon and rectal) cancer in England are shown at Figure 9, and survival rates at Figure 10. The reasons why survival rates have improved and mortality rates fallen are unclear but could be a combination of earlier diagnosis, improved surgery and wider use of post-operative chemotherapy.

Prostate cancer: mortality rates are falling, although increases in incidence and survival are more difficult to interpret

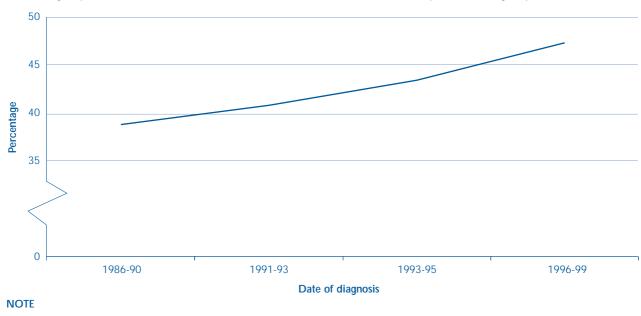
1.11 Figure 11 shows changes in prostate cancer incidence and mortality over time. The reasons for the underlying increase in prostate cancer are not fully understood but the increase in the rate of incidence is in part due to the impact of wider use of the Prostate Specific Antigen (PSA) test. This can lead to cancers being picked up which might not have otherwise have caused problems during a man's lifetime or led to the man seeking medical advice.

### Bowel Cancer - slowly rising incidence and declining mortality over time in England and Wales

Incidence rates have risen very slowly for two decades, while mortality rates have fallen by over 25 per cent reflecting improvements in the quality of treatment.







Over a ten-year period relative survival rates for colon cancer have increased from under 40 percent to nearly 50 per cent.

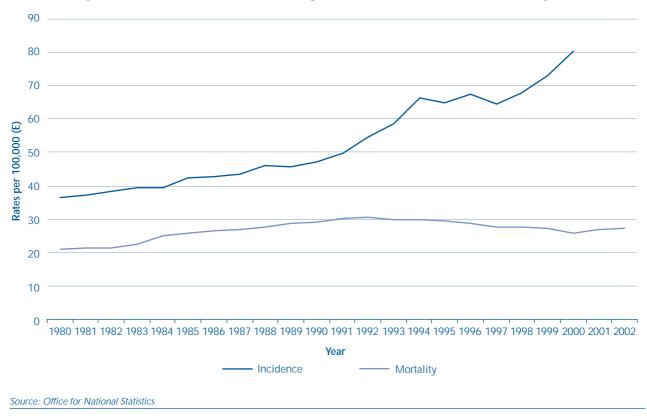
Source: Office for National Statistics

11

### Trends in prostate cancer incidence and mortality in England

The introduction of the Prostate Specific Antigen (PSA) test in the early 1990s led to a big increase in the diagnosis of prostate cancer, although this was on top of an existing underlying trend of more cases. The mortality rate has started to decline in recent years. No research has yet shown a link between earlier detection through increased use of the PSA test and lower mortality rates.

\*Colon cancer forms the large majority of bowel cancer cases - latest data not available for rectal cancer.



1.12 As Figure 12 below shows, five-year relative survival rates for prostate cancer have increased from 42 per cent to 64 per cent since the early 1990s. The increase is partly accounted for by earlier detection of the cancer through increased use of the PSA test rather than increased effectiveness in dealing with the disease, although the quality of treatment may also be improving.

### Incidence, mortality and survival rates are not uniform geographically

Breast cancer: mortality rates can vary considerably for areas with similar incidence rates

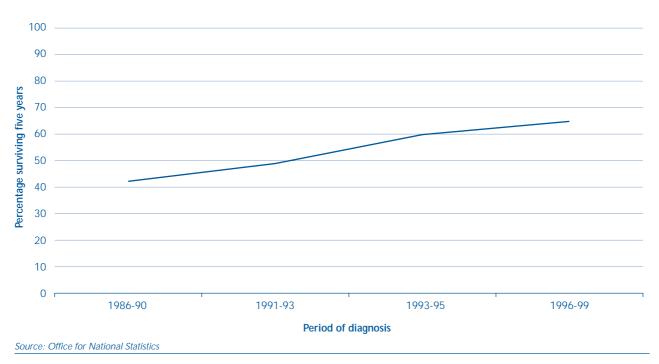
1.13 Figure 13 shows how mortality varies by Strategic Health Authority (SHA) in relation to incidence for breast cancer. Breast cancer incidence is generally higher in southern SHAs with higher levels of affluence. Mortality is not clearly related to incidence. Figure 14 shows five-year relative survival rates. Survival rates are higher in London and the South East. High relative survival rates and low mortality in relation to incidence emphasise that the outcomes for this disease are now good.

Lung cancer: there is a close link between incidence, mortality and deprivation

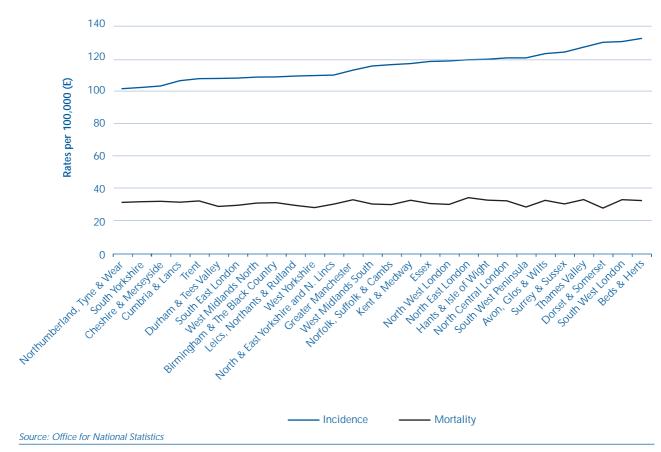
1.14 Figure 15 shows how mortality varies in relation to incidence for lung cancer across SHAs. Incidence and mortality rates vary across England much more than for other cancers, cancers with incidence and mortality rates for the worst affected SHA being approximately twice that for the least affected SHA. Figure 16 shows poor 5-year relative survival rates in all areas. The close relationship between incidence and mortality rates, and uniformly low survival rates, emphasise how deadly the disease is, reflected in the fact that average life expectancy after diagnosis is 4 months.

#### 12 Improvements in relative survival for prostate cancer

Increased use of the PSA test probably plays a large role in increased survival since prostate cancer takes decades to grow, and the test may well diagnose the disease many years before it would otherwise have become apparent. Information from the British Association of Urological Surgeons shows that the proportion of tumours diagnosed at an early stage (stages I and II) rose from 52 per cent in 1999 to 60 per cent in 2002.

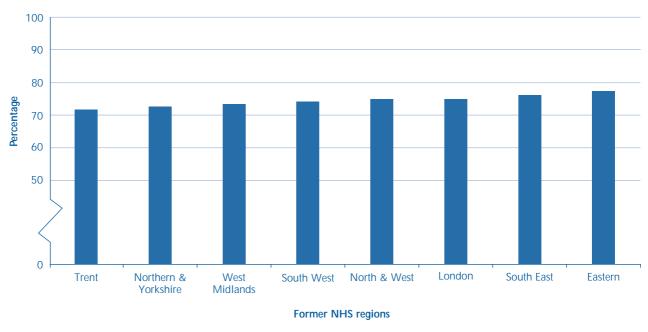


### 13 Breast cancer mortality (1999-2001) varies with incidence (1997-99) among Strategic Health Authorities



Mortality rates can vary by as much as 20 per cent between Strategic Health Authorities (SHAs) with almost identical levels of incidence. Those SHAs with higher levels of incidence generally have more affluent populations.





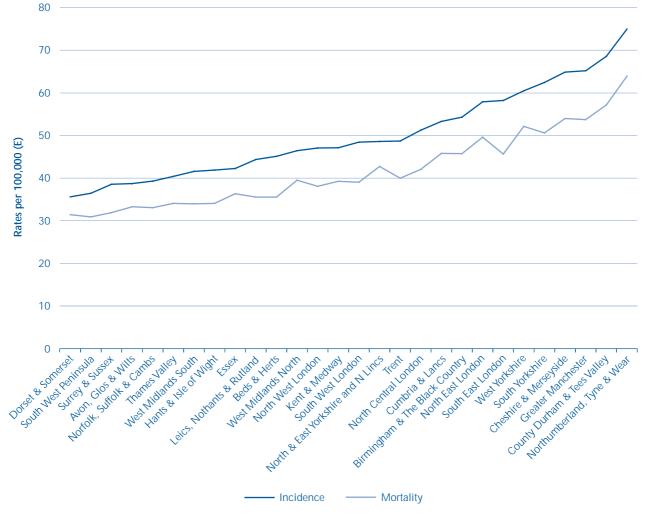
Five-year survival rates are generally higher in more affluent areas.

Source: Office for National Statistics

part one

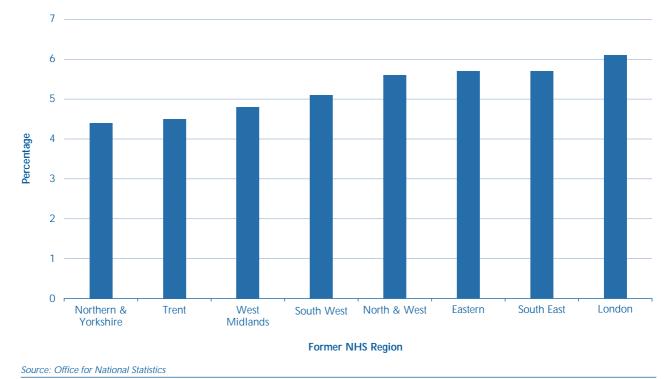
### 15 The close relationship between incidence rates (1997-99) and mortality rates (1999-2001) for lung cancer, by Strategic Health Authority

Levels of lung cancer incidence and mortality are closely linked. Strategic Health Authorities with the highest rates of both are also those with the highest levels of deprivation, since the prevalence of smoking is closely related to deprivation.



Source: Office for National Statistics

18



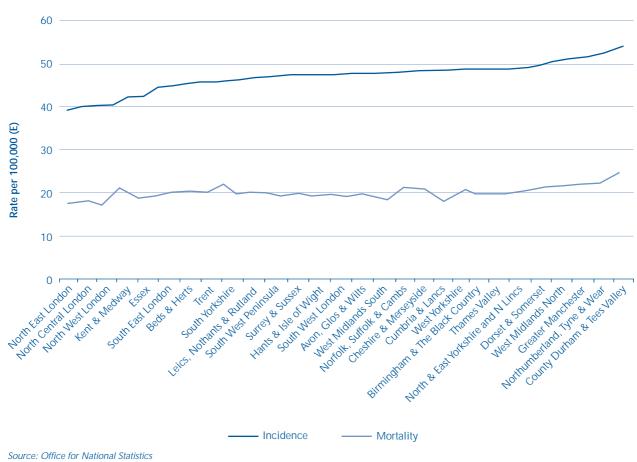
### 16 Uniformly low 5-year relative survival rates for lung cancer for patients diagnosed 1993-95

Lung cancer survival is uniformly low across the country, but in relative terms is considerably higher in London than in the former Northern and Yorkshire region.

Bowel cancer: incidence but not mortality is generally higher in the north and survival rates are somewhat better in more affluent areas

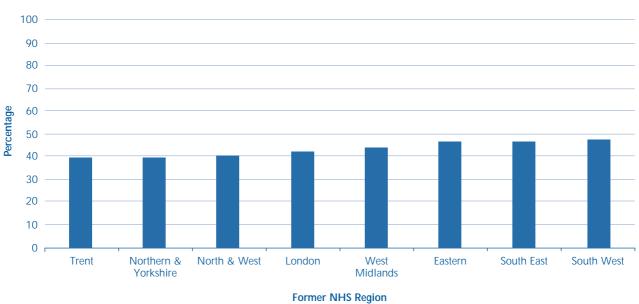
1.15 The relationship across SHAs between bowel cancer incidence and mortality rates is shown at Figure 17. Incidence rates for bowel cancer are not generally higher for deprived groups except in the case of rectal cancer among men. Figure 18 shows five-year survival rates for colon cancer, which constitutes the great majority of cases of bowel cancer. Survival rates are somewhat better in more affluent areas.

### 7 The relationship between incidence and mortality rates for bowel cancer in SHAs



There is some linkage between incidence and mortality rates, but some areas with similar incidence rates have noticeable differences in mortality rate.

### 18 Higher relative survival rates for colon cancer in the south for patients diagnosed in 1993-95



More affluent areas of England have slightly higher survival rates.

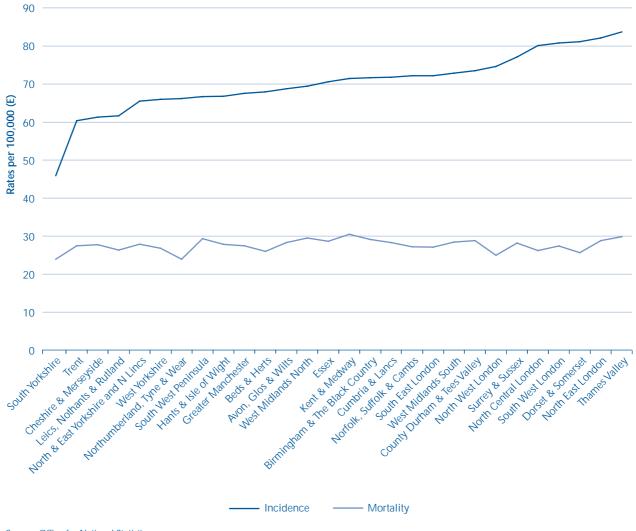
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Prostate cancer: mortality varies considerably for areas with a similar rate of incidence, and survival rates favour London and the South

1.16 Figure 19 shows variations in reported incidence and mortality rates by SHA for prostate cancer. Prostate cancer incidence is generally higher in southern SHAs with higher levels of affluence. Figure 20 shows five-year survival rates. Survival rates are lowest in the former Trent and Northern and Yorkshire regions. This may reflect lower detection rates of early stage prostate cancer because of lower uptake of PSA testing.

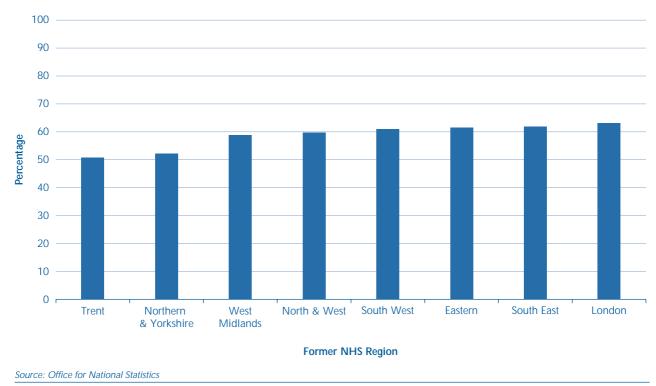
#### 19 Prostate cancer mortality varies between areas with similar incidence rates

Incidence rates vary considerably across the country. Mortality rates can vary by as much as 20 per cent between SHAs with almost identical levels of incidence.



Source: Office for National Statistics

### 20 Prostate cancer relative survival for patients diagnosed 1993-95 by former NHS Region



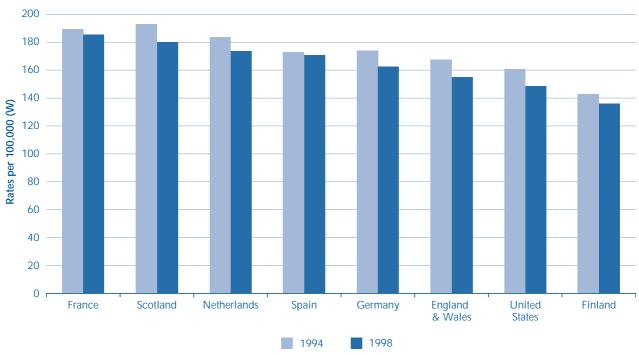
Survival is lower in the former Trent and Northern and Yorkshire regions.

England's position is improving relative to other comparable countries

England's mortality rates have improved in relation to other comparable countries in the 1990s

1.17 Figures 21 and 22 show how cancer mortality in England and Wales (with whom we are grouped for international comparisons) compares with other countries. Some countries were excluded from these comparisons because of small populations or lack of recent data. Mortality rates for men in England and Wales in 1998 were better than in France, Spain and Germany but worse than those in the USA and Finland. Mortality rates for women in England and Wales in 1998 were worse than those for the comparator countries. These rates are strongly influenced by deaths from lung cancer, which reflect historical trends in smoking rates.

### 21 Varying International mortality rates for all cancers - men



On overall cancer mortality rates for men, England and Wales compare favourably with many other countries such as Spain, France and Germany.

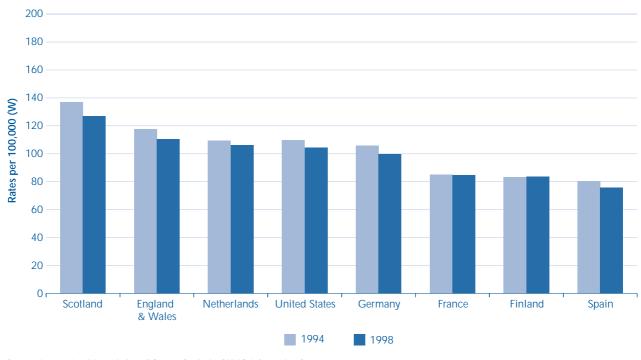
### NOTE

Countries on the left hand side of the graph have higher mortality rates.

Source: International Association of Cancer Registries/WHO Information System

#### 22 Varying international mortality rates for all cancers - women

England and Wales compare much better with other countries on cancer mortality for men than for women because of the historical proportions of smokers of each sex relative to other countries.



Source: International Association of Cancer Registries/WHO Information System

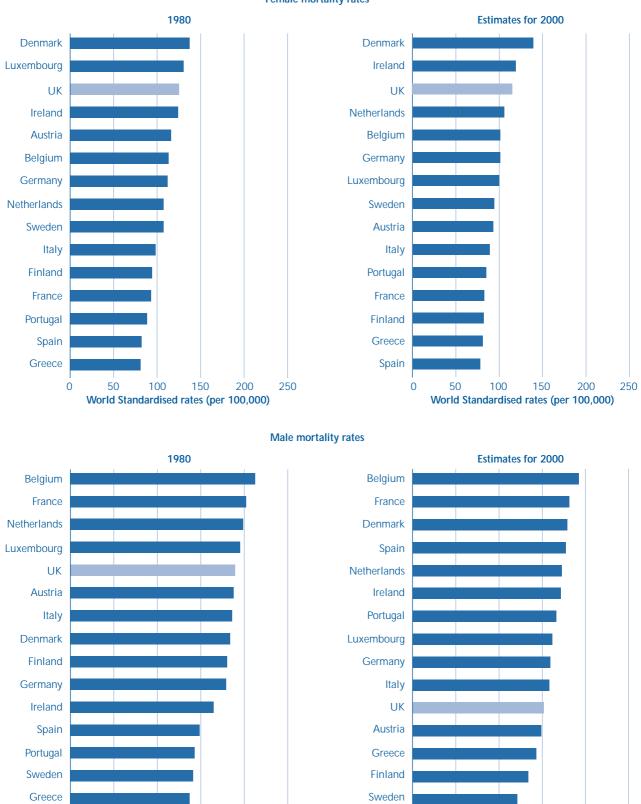
- 1.18 The performance of the United Kingdom as a whole in reducing cancer mortality in comparison with other European Union countries has been impressive in the last twenty years for men but less so for women (see Figure 23). This is largely attributable to earlier decline in tobacco use among British men, and earlier take up of tobacco among British women, compared with other countries.
- 1.19 Further analysis of mortality rates relative to other countries for the major cancers can be found at Appendix 3. The main messages are:
  - Breast cancer mortality rates in England were among the worst in the developed world in the late 1980s. Since then the fall in mortality rates has been the steepest in the world. Despite this, breast cancer mortality remains high in relation to that in comparable countries;
  - Lung cancer mortality rates reflect where each country is in the cycle of tobacco use and stopping smoking. Hence, England and Wales compare well with other countries for mortality in men but, on current data, less so for women. Women started smoking earlier in the UK than in other comparable countries and so cancer incidence rates and associated deaths are higher at the moment in comparison to other countries. As lung cancer incidence and mortality trends are now downwards for women in England and Wales but incidence trends for women in other countries are now generally on an upward path, mortality rates relative to those in other countries should improve;
  - Mortality rates for intestinal<sup>vi</sup> cancer (the vast majority of cases are colon and rectal cancer) for England and Wales are comparable with those of other countries (especially for women) with a clear downward trend;
  - Prostate cancer mortality rates remain high for England and Wales compared with other countries. The reasons are unclear.

England's cancer survival rates in the 1990s were lower than those in some other countries, but are improving

- 1.20 When comparing trends in England's five-year survival rates against other European countries the source of data is the EUROCARE project, established in 1989 to measure and explain international differences in cancer survival across Europe and overseen by a Working Group made up of statisticians and epidemiologists from cancer registries across Europe. The graph overleaf show results from the EUROCARE-2 and EUROCARE-3 studies, covering people diagnosed between 1985 and 1994 and followed up to 1999. As such, these data cover the period up to the introduction of the NHS Cancer Plan and the survival rates for England will be lower than the more recent data shown earlier in this part of the report.
- 1.21 **Figure 24** shows comparisons for European countries which have cancer registry data covering at least one quarter of their population. For this reason countries such as France and Germany are excluded<sup>3</sup>.
- 1.22 Survival rates from these periods for all the major cancers are higher in the USA than Europe, although, prior to expansion of geographical coverage in 2001, survival data from the United States (known as the Survival, Epidermiology and End Results (SEER) programme) was drawn from registries covering approximately 14 per cent of the United States populationvii. Five-year relative survival rates for all cancers in the United States were 56 per cent for persons diagnosed in 1987 and 63 per cent for persons diagnosed in 1992. Recent research on breast cancer has shown that the higher survival rates for the disease in the registries in the SEER programme compared with Europe (around 85 per cent for women diagnosed in the early 1990s) are linked to diagnosis of the disease at a less advanced stage in the United States.viii
- 1.23 More details of survival rates for the major cancers relative to those in other countries can be found at Appendix 4. This shows a steady improvement in England's performance across the cancers. This pattern is also found in some, but not all, of comparator countries, but the picture varies from cancer to cancer. Recent research on breast cancer survival has again linked variations in survival rates across Europe in the early 1990s to the cancer being diagnosed at a later stage in some countries than others.<sup>ix</sup>

### 23 How the UK has reduced cancer mortality in relation to other EU countries

Between 1980 and 2000 UK cancer rates for men fell from 11th to 5th lowest in the European Union, while UK cancer mortality rates for women remained 3rd highest.



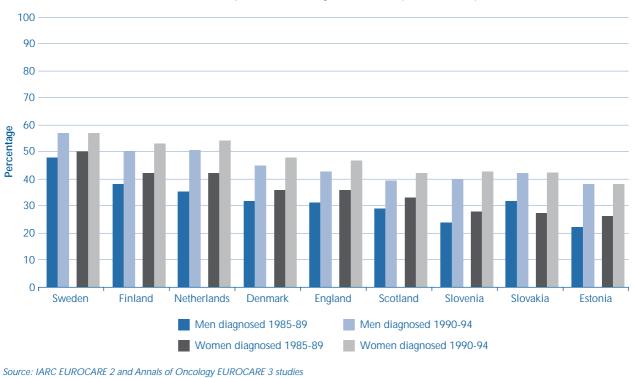
Female mortality rates

Source: Boyle et al. Measuring progress against cancer in Europe. Annals of Oncology 14: 1312-1325, 2003

World Standardised rates (per 100,000)

World Standardised rates (per 100,000)

### 24 Increasing five-year survival rates across Europe in the 1990s



Survival rates continued to rise across most of Europe in the 1990s. England's rate of improvement compares well.

# Part 2

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

- 2.1 The Calman-Hine report<sup>x</sup>, produced under the leadership of the Chief Medical Officers for England and Wales and published in 1995 recognised the need for a major step forward in the provision of cancer care in England. Most importantly, the report outlined a framework for the management of patients already diagnosed with cancer, with the emphasis on high quality, patient-centred care. A series of interlinked cancer centres and local units covering the entire country were to be developed, within a series of geographically defined cancer networks to modernise and integrate services. There are now 34 Cancer Networks, each covering a population of around 1-2 million people. Implementation was the responsibility of the former NHS Regions although no specific additional resources were made available when the report was published.
- 2.2 Following the appointment of a National Cancer Director in 1999, the NHS Cancer Plan<sup>xi</sup> published in 2000, set out the first comprehensive strategy to tackle the disease and deliver the fastest improving cancer services in Europe, so that by 2010 England's five-year survival rates would compare with the best in Europe. The Plan's objectives are:
  - to save lives;
  - to ensure people with cancer get the right professional support and care as well as the best treatments;
  - to tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals;
  - to build for the future through investment in the cancer workforce, through strong research and through preparation for the genetics revolution, so that the NHS never falls behind in cancer care again.

A three year progress report on the Cancer Plan was published in 2003<sup>xii</sup> setting out the achievements that have already been made and the challenges that lie ahead.

- 2.3 In this part of the report we assess the key initiatives being undertaken to reduce the risk of cancer incidence and to improve survival rates. Success in these areas should also lower mortality. We do not attempt to assess progress against all of the targets and commitments set out in the NHS Cancer Plan, which will be examined in our later reports.
- 2.4 A wide range of actions can contribute to reductions in the burden of cancer across the country and to improvements in cancer outcomes. Some of these relate to the behaviour and lifestyles of people as individuals, some to measures taken by society as a whole and others to actions taken by the NHS:
  - lifestyle factors affect the incidence of some cancers. For example smoking increases the risk of several types of cancer (including lung cancer), while eating a healthy diet can protect against the development of some cancers;
  - screening can help to reduce the mortality for certain cancers, by picking up cancers or precancerous abnormalities before symptoms develop or are apparent;
  - early presentation to GPs by patients who develop symptoms consistent with cancer can enable the diagnosis to be made while the disease is still curable, leading to improvements in survival rates and reductions in mortality;
  - once patients have been referred for assessment, rapid and accurate diagnosis and the delivery of the best available treatment maximise the chance of survival. A map of the care pathway covering assessment, diagnosis and treatment can be found at Appendix 5.
- 2.5 This part of the report examines progress in each of these areas for the four major cancers (breast, lung, bowel and prostate).

### The NHS Stop Smoking programme, supported by other anti-tobacco measures, is a priority because of the contribution of smoking to cancer rates, and has made a promising start

- 2.6 Among lifestyle influences on cancer, tobacco use has by far the greatest impact on overall cancer incidence, mortality and survival rates. We therefore look here at measures to prevent cancer by reducing tobacco use, while the wider context of preventive measures being taken by the NHS and other parts of government, in areas such as nutrition and physical activity, will be examined in our future report on the NHS Cancer Plan.
- 2.7 One-third of all cancer deaths, and 90 per cent of lung cancer deaths, are due to smoking. The Government's tobacco strategy has a number of strands, some involving the Department of Health:
  - reducing tobacco promotion. The Tobacco Advertising and Promotion Act 2002 provided for a ban on tobacco advertising, promotion and sponsorship;
  - communication and education. As part of this programme the Department of Health has given £15 million over 3 years to charities to develop media campaigns about the dangers of smoking;
  - tobacco regulation. As of September 2003 cigarette packets carry larger and more stringent health warnings and terms such as "light" and "mild" are banned;
  - reducing availability and supply of tobacco. Smuggled tobacco accounts for about one fifth of the market. HM Customs and Excise have cut the illicit market share in cigarettes from 21 to 18 per cent between 2000-01 and 2002-03x<sup>iii</sup>; and
  - reducing exposure to second-hand smoke. Recent media campaigns have raised awareness of the health risks from second-hand smoke.
- 2.8 A key contribution of the NHS to the strategy is its Stop Smoking services. Expenditure on these services during 2002-03 was £24.5 million. Research has demonstrated that stopping smoking at any point well into middle age will reduce the risk of cancer in the future<sup>xiv</sup>. In 2002-03 just over half of those people setting a quit date as part of a NHS Stop Smoking service were still not smoking four weeks later. To date some 340,000 people reported that they were still not smoking four weeks after their quit date. There is currently no national requirement to follow-up these people after 4 weeks though evidence from clinical trials suggests that around 30 per cent of those people not smoking at four weeks will still not be smoking after 12 months. A pilot study is looking further at this question.

- 2.9 **Figure 25** shows how successful Stop Smoking services were in 2002-3 in different parts of the country, as measured by the numbers quitting for at least 4 weeks. A seven fold variation in the number of 4 week quitters per 100,000 population was observed in 2002-03 between the highest and lowest performing Strategic Health Authorities.
- 2.10 An early objective of the NHS campaign to stop people smoking was to target deprived areas. It is known that smoking prevalence is linked to socio-economic status. Manual workers are more likely to smoke. In 2001 32 per cent of manual workers smoked compared with 21 per cent of non-manual workers.
- 2.11 Research in 19 former district health authorities shows that, in general, schemes were attracting smokers from the most disadvantaged areas<sup>XV</sup>, though a qualitative review of English NHS Stop Smoking projects among manual workers in 2003<sup>XVI</sup> showed that success varied in different parts of the country in part because some groups of smokers can be harder to enrol in schemes than others. For example, there is a large Bangladeshi population in East London whose men smoke more than other ethnic groups<sup>XVI</sup> and who change address frequently.

### Screening populations before cancer symptoms are apparent has improved outcomes for breast cancer and will do for bowel cancer

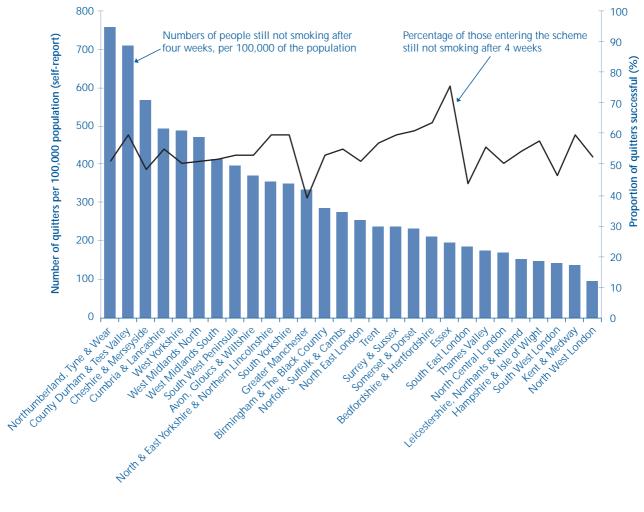
2.12 The Department of Health has implemented nationally co-ordinated screening programmes for breast and cervical cancer, which have been praised by other countries. The Government has also made a commitment to introducing bowel cancer screening, in line with a commitment in the NHS Cancer Plan to extend screening programmes and introduce new programmes if it is proven that they will save lives.

The breast cancer screening programme has contributed to a sharp fall in breast cancer mortality

2.13 The Office of National Statistics estimated that by 1998 breast cancer mortality rates were between 5 and 11 per cent lower than they would have been without the introduction of the national breast-screening programme in 1988<sup>xviii</sup>. Recent research in the north west of England found that far more cases of advanced cancer at the time of diagnosis were found in areas with lower screening take-up<sup>xix</sup>.

#### People who accessed Stop Smoking services and were still not smoking 4 weeks after quitting, by Strategic Health Authority, 2002-03

Almost 125,000 smokers quit for at least four weeks in NHS Stop Smoking schemes in 2002-03. Success rates varied between approximately 40 and 80 per cent, depending on SHA and highest quit rates were observed in deprived northern SHAs.

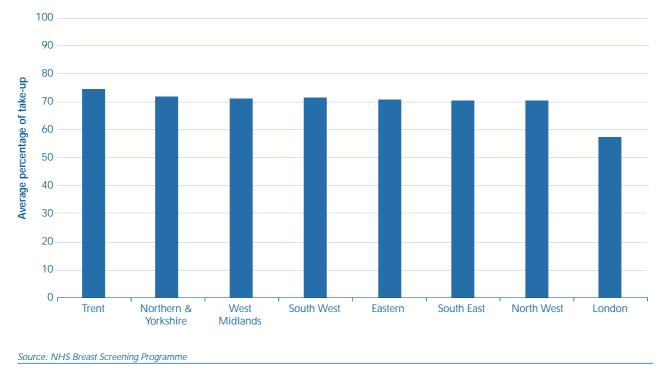


Source: Department of Health and Office for National Statistics

- 2.14 Women aged 50-64 (identified through GP lists) are routinely invited by Primary Care Trusts for screening every three years. Breast screening units are under increasing pressure and some units have had to extend their three-yearly cycle by several months. Units are committed to extending screening to women aged 70 by the end of 2004, as women in this age group have a higher risk of developing the disease and pilot studies have shown good uptake rates and cancer detection rates in this age group. This extension of the screening programme, together with the taking of an additional view of the breast at every screen ('two-view mammography'), will increase workload by approximately 40 per cent. The vast majority of breast screening units have now implemented two-view mammography, which almost certainly contributed to a 13 per cent increase in the number of cancers detected in 2002-03.
- 2.15 The NHS intend to achieve this expansion through the establishment of a new career structure for radiography designed to widen access to radiography careers and improve retention<sup>xx</sup>, as well as the procurement of new mobile units and new building projects.
- 2.16 The proportion of eligible women screened within the previous 3 years has increased steadily from 64 per cent in 1995 to around 70 per cent from 2000 to 2003, while take-up (annual rate of attendance by eligible women invited for screening) has remained between 75 per cent and 77 per cent. Figure 26 shows how take-up varies around the country, with the lowest rates being observed in London. London also has a higher proportion of eligible women who have never been screened (at March 2003) 22 per cent within the Government Office for London region compared with 13 per cent across England as a whole.

### 26 Regional variations in the take-up of breast cancer screening by women who were invited during the 3-year cycle up to March 2002





2.17 There are several contributory factors to low take-up:

- Socio-economic deprivation. People in the most deprived areas often make less use of healthcare services;
- Areas with high proportions of minority ethnic groups. This effect is not, however, uniform across all minority groups and appears more prevalent for those of African, Afro-Caribbean and Chinese origin. A range of local initiatives are underway around the country to address these issues - for example, grouping invitees from particular ethnic groups; and
- High transient populations in London. There is a strong correlation between areas with a high proportion of people moving within the previous year (as recorded by the 1991 census) and areas of low screening uptake.

### Screening for bowel cancer will reduce mortality when it is introduced

2.18 Following research results which indicated that a screening programme could cut bowel cancer deaths by 15 per cent, the NHS ran a screening pilot scheme at two sites in the UK from 2000-02 to establish the acceptability and feasibility of a national screening programme based on the Faecal Occult Blood (FOB) test - a test for invisible blood in the faeces - among men and women aged 50 to 69.

- 2.19 The schemes achieved a 60 per cent uptake among the target population, with lower rates among younger men in their early 50s and, as for breast screening, among those from deprived areas and ethnic minorities. These lower rates applied to both the initial and the follow-up tests. The evaluation of the pilot concluded that the benefits of the programme justified a national roll-out.
- 2.20 One important factor in any roll-out is the resource impact of screening on other parts of the NHS. The evaluation<sup>xxi</sup> found that the additional workload for other parts of the NHS varied. There was only a marginal impact on GP consultations, but a far greater impact on hospital services in the following areas:
  - Increasing numbers of colonoscopy examinations for patients with symptoms and through follow-up testing;
  - Additional consultant sessions for outpatient attendance and review and communication with GPs following testing;
  - There was evidence that screening requirements increased waiting times for other patients with symptoms who were referred outside the screening system;
  - Additional work for surgeons and oncologists after a positive diagnosis; and
  - Increases of up to 30 per cent in workload for pathologists.

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- 2.21 Piloting has now entered a second two year phase and will target low attendance groups from the first phase, assess whether people will re-attend for screening, investigate the management of borderline results, and look at the possible use of other forms of FOB test.
- 2.22 As part of the NHS Bowel Cancer Programme, launched in February 2003, a Bowel Cancer Screening Working Group has been set up. The Group's first task has been to commission an option appraisal of possible screening methodologies. One alternative screening test to the FOB test under consideration is flexible sigmoidoscopy, an endoscopic examination of part of the large bowel. This test has the potential to reduce the level of incidence of the cancer and reduce the frequency of testing although it is more invasive. The Group await the results of a large UK trial. Any timetable for national roll-out will have to take into account the additional resource demands on hospitals. A new structure to greatly increase capacity in endoscopy training will help to create the required workforce for a national screening programme.

There is no evidence to support screening for lung and prostate cancer using techniques currently available

- 2.23 The large majority of patients with lung cancer are only diagnosed when the disease is at an advanced stage, with few patients surviving beyond one or two years. Unfortunately, as yet, research has not established an effective screening test. However, large-scale trials are underway in Europe and the United States to assess the effectiveness of scanning techniques for screening in high risk populations.
- 2.24 At present there is no reliable evidence that any technique for prostate cancer screening reduces mortality, although any screening programme for prostate cancer is likely to be based around the Prostate Specific Antigen (PSA) test. This test can enable the diagnosis of prostate cancer to be made at a treatable stage but it is also rather inaccurate. Raised PSA levels are found in appreciable numbers of men without the disease. In addition, the test may fail to identify some men with low levels of PSA who do have the disease. The situation is complicated by a lack of research evidence about the appropriate treatment for men diagnosed at an early stage of the disease. The Department of Health is funding a £13 million trial of treatments for localised prostate cancer detected by PSA testing which will help to establish which treatment is most effective and provide information that will help when considering whether a screening programme would be justified.

2.25 Research to improve the reliability of the PSA test is continuing. In the meantime the Department has introduced the Prostate Cancer Risk Management Programme to aid GPs in counselling men who are worried about prostate cancer, ensuring they make an informed choice about whether or not to have a PSA test and to ensure consistent standards in analysis and interpretation of results.

## People in England tend to be diagnosed with cancer at a more advanced stage than in other countries

- 2.26 An international workshop of cancer epidemiologists and other experts held during the preparation of the NHS Cancer Plan<sup>xxii</sup> examined available evidence on differences in cancer survival rates. The workshop concluded that the lower survival rates reported in England than for other western European countries were to a large extent real, and not the result of differences in data measurement The workshop also concluded that patients in England tend to have more advanced cancer at the time of diagnosis than in some other countries, at least for breast and bowel cancer.
- 2.27 Older people and those from deprived areas are more likely to be diagnosed with cancer at a more advanced stage:
  - older people. Analysis of new registrations in 2000 for cancer in four English cancer registries (where data on stage of cancer were available in more than 75 per cent of cases) reveals that women over the age of 65 were diagnosed with more advanced breast cancer. Research carried out in the late 1990s found a strong relationship between advanced stage of breast cancer at diagnosis and increasing age<sup>xxiii</sup>. There is also evidence that older women are more likely to delay seeking medical advice. Registries did not, however, show any increase in the proportion of late-stage cancer among older people for bowel (colon or rectal) cancer;
  - people from deprived areas. For example, in the West Midlands registry area, for new cases of breast cancer between 1994 and 1998, 31 per cent of women in the most affluent localities presented with the least advanced stage of the disease, compared to 24 per cent of women in the most deprived localities. Conversely, 15 per cent of the women in the most deprived localities presented with advanced disease, compared to 9 per cent of women in the most affluent localities<sup>xxiv</sup>.

Diagnosis with symptoms at a more advanced stage in England is a combination of patient, GP and hospital factors

- 2.28 Several factors may contribute to more advanced cancer at the time of diagnosis:
  - Delay in the patient coming forward with symptoms;
  - Delay in onward referral by the GP; and
  - Delay in carrying out diagnostic tests within the hospital system.

Little is known about the extent of patient delay in England but it is likely to be caused by a combination of factors, including lack of symptom awareness and a reluctance to seek medical advice when they are identified

- 2.29 Little research has been done for most cancer types to quantify the extent of delay by patients in presenting to their GP with symptoms consistent with cancer. Research with breast cancer patients published in 1999 found that around one third of women had delayed more than 3 months before approaching a GP, and that delays of this duration were associated with significantly poorer five year survival rates<sup>xxv</sup>. However, for the other major cancers, there are no similar benchmarks.
- 2.30 Delay may be due in part to a lack of awareness of cancer symptoms or to a reluctance to come forward when symptoms are noticed. Surveys regularly attest to low levels of public awareness of symptoms associated with the most common cancers. For example:
  - a survey of women over 50 in 2003 found that two-thirds did not realise the risk of breast cancer increased with agexxvi.
  - a survey of the public about bowel cancer in 1999 found only 31 per cent able to correctly identify any symptom<sup>4</sup> of the disease<sup>xxvii</sup>; and
  - a survey of men in 1999 found that only one-quarter of them considered that they knew "a lot" or "a fair amount" about prostate cancerxxviii;
- 2.31 In 2000 the Department undertook to develop a cancer public awareness programme. It commissioned several pieces of research which will provide information on why patients delay seeking help from their GP when symptoms become apparent. The results of this research are expected during 2004 and will inform the development of strategies to promote awareness and to encourage the seeking of help at an earlier stage. The Department has also funded the voluntary sector in this

area, for example, CancerBACUP was funded to produce a version of the NHS GP referral guidelines for patients and the National Cancer Director discussed work on public awareness with the Prostate and Bowel Cancer Advisory Groups. He also intends to discuss awareness with the newly formed Lung Cancer Advisory Group.

2.32 Research shows that such action can be effective. Public education in Scotland and Australia about the dangers of melanoma (a form of skin cancer) led to a significant reduction in patient delay and resulting diagnosis with less advanced cancer<sup>xxix</sup>. National campaigns to increase awareness of cancer symptoms are not without potential problems, however. They could also cause considerable anxiety in vulnerable patients without cancer, and create large numbers of the "worried well". This could impact significantly on GP workloads and on the number of patients being referred to hospitals.

General Practitioners (GPs) are required to refer urgently patients they suspect of having cancer, but can have difficulty identifying those patients accurately

Not all GPs are benefiting from measures to assist accurate identification of symptoms

- 2.33 GPs have a crucial role to play in ensuring that patients with symptoms that might indicate a cancer are directed as quickly as possible to specialists for assessment, while not swamping diagnostic services with large numbers of patients with very little likelihood of having the disease.
- 2.34 While it can be relatively easy to identify some symptoms as being indicative of the likely presence of a cancer, such as a breast lump in an older woman, it can be much more difficult to decide whether more non-specific symptoms, such as a persistent cough, are likely to be due to cancer. In order to assist in this task, the Department of Health sent all GPs a set of guidelines for the referral of suspected cancer patients in 2000, providing detailed guidance on how to identify patients requiring urgent referral.
- 2.35 When we surveyed GPs (see Appendix 2), just under half of the responding GPs stated that they had both read the referral guidelines and had found them useful. Among GPs who claimed not to find the guidance useful the most common reason given was "that it did not add to their existing knowledge". NICE is currently revising the referral guidelines.

The policy to refer suspected cancer cases urgently for assessment is meeting targets but some of those with cancer do not benefit from it

- 2.36 For many years waiting times for new patient assessments have been a problem within the NHS. To address this, NHS Patients have therefore been divided into 'urgent' and 'routine' groups, based on the GPs assessment of the likelihood of the patient having a serious underlying problem. Following an audit of waiting times for cancer patients relating to patients diagnosed in October 1997, the Department introduced a new policy that all patients referred urgently by their GP with suspected cancer should be assessed by a specialist within two weeks. This was introduced for breast cancer in 1999 and for other cancers in 2000. In the most recent three month period (July - September 2003) 99 per cent of urgent referrals were assessed within 2 weeks when the GP notified the hospital within 24 hours of seeing a patient, and 88 per cent when they did not.
- 2.37 GPs responding to our survey told us that, of patients they had referred in the previous 12 months who were subsequently diagnosed with cancer, an indicative figure of approximately two thirds had been referred urgently and one third routinely. Of the 4 major cancers, lung cancer patients were the most likely to be referred urgently and prostate patients the least likely (which probably reflects the uncertainty of interpreting results of the PSA test). Research in the 1990s showed the same ordering for the major cancers<sup>XXX</sup>. There is no evidence base to indicate what would be a realistic proportion of accurate referrals for GPs if best practice was followed.
- 2.38 In our consultant survey, see Appendix 2, we asked what proportion of people referred urgently to them by GPs had, in their professional opinion, been referred appropriately (which is not the same as actually having cancer). Respiratory (lung) physicians gave a median proportion of 80 per cent of urgent referrals as appropriate. This high figure reflects the fact that it is good practice for GPs to carry out a chest x-ray as a pre-assessment measure before referring patients. For colorectal (bowel) surgeons the median proportion referred appropriately fell to 50 per cent. There is much less scope for GPs to carry out an equivalent preliminary test, such as endoscopic examination, in primary care.
- 2.39 Feedback from hospitals to GPs on the quality of their referrals is one potential way of improving referral accuracy. However, only 21 per cent of the GPs in our survey said that they receive feedback of this type.

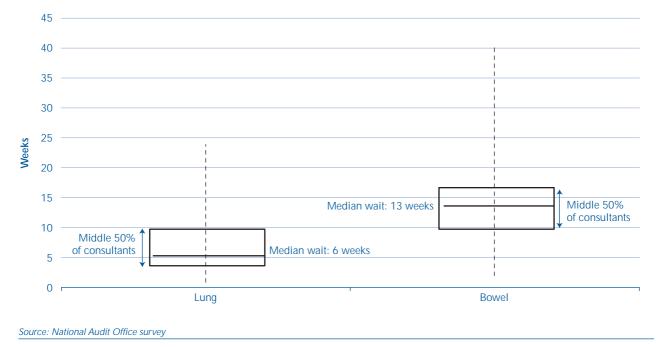
2.40 Even when patients are referred appropriately it is inevitable that some will not turn out to have cancer. Respiratory (lung) physicians in our survey indicated that between one third and one half of those referred urgently were actually diagnosed with lung cancer. For colorectal (bowel) surgeons this figure was around 10 per cent. This may be due largely to the fact that symptoms of bowel cancer can be very similar to those of non-cancerous conditions. The Association of Coloproctologists of Great Britain and Northern Ireland estimates that 97 per cent of patients who present to their doctor with rectal bleeding do not have bowel cancer, although it is a recognised symptom of the disease<sup>xxxi</sup>.

Existing targets to speed up the treatment of patients referred urgently by GPs are being met, but patients referred routinely who may subsequently be diagnosed with cancer can take longer than this to see a specialist

- 2.41 Patients with breast symptoms referred urgently by their GP to be seen by a specialist within two weeks, who are then diagnosed with cancer, must receive treatment within two months of the original referral and within one month of diagnosis. Performance against both of these targets was 98 per cent for the most recent quarter<sup>xxxii</sup>. These targets will be extended to other cancers in 2005.
- 2.42 For people who were assessed as routine referrals, waiting times to be seen by a consultant can be considerably longer than two weeks. In our survey of consultants, the median waiting time for patients referred routinely with lung or bowel symptoms by GPs was reported to be 6 weeks and 13 weeks respectively (see Figure 27 overleaf). In the case of prostate cancer, a high proportion of people are diagnosed with the disease at an early stage. However, early assessment is still desirable.
- 2.43 Some consultants check the content of referral letters (or proformas) from GPs and reprioritise patients to the "urgent" category where it is apparent that the patient comes into a high risk group. However, patients who are deemed urgent by their GP should always be handled as urgent cases. In addition to this, some colorectal services use questionnaires completed by the patient to provide additional information on the level of risk of serious disease being present and this may also be used for prioritisation of patients.

### 27 Time before assessment by consultant for patients referred routinely by GPs, some of whom are subsequently diagnosed with cancer

According to consultants responding to our survey, patients with bowel symptoms referred routinely by GPs wait much longer than those with lung symptoms, typically 5 to 10 weeks for lung referrals and 10 to 15 weeks for bowel referrals. Some of these will subsequently be found to have cancer.



2.44 Research carried out from 1999 to 2001 used a computer-analysed patient questionnaire to record symptoms on a systematic basis and determine the referral path. It was shown to provide fuller information and be just as effective at identifying patients with likely cancer as the conventional GP letter to a consultant, but required far fewer of the patients to be classified as urgent referrals<sup>xxxiii</sup>. We asked GPs in our survey whether they used a standard proforma for recording symptoms when making referrals, but only 30 per cent of the GPs who responded to our survey actually did so.

### Measures are being introduced to address delays for patients awaiting diagnostic tests

### There can be long waits for some endoscopic procedures but there are solutions

2.45 Endoscopy involves the use of a more or less flexible viewing instrument for the visual inspection of any cavity in the body and to collect tissue for analysis - for example, sigmoidoscopy and colonoscopy for the assessment of bowel symptoms and bronchoscopy for the assessment of lung symptoms. In recent years average waiting times of several months for colonoscopy have become commonplace. The demand for gastro-intestinal endoscopic procedures has risen substantially, as shown in **Figure 28**. In addition, a survey of practice in colonoscopy units in the UK carried out in 2000 revealed continuing concerns about the quality of examinations carried out<sup>xxxiv</sup>.

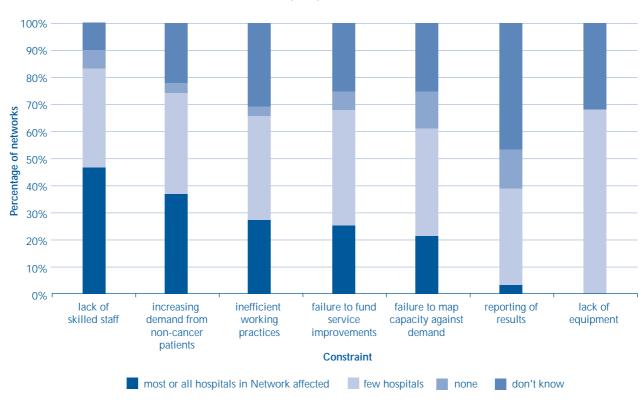
### 28 Increases in endoscopic procedures over time

|  | 1995-96          | 2000-01            | Increase (%) |
|--|------------------|--------------------|--------------|
| Bowel examinations:<br>Flexible sigmoidoscopy<br>Colonoscopy | 72,452<br>93,237 | 134,109<br>153,897 | 85<br>65     |
| Lung examinations:<br>Bronchoscopy and<br>mediastinoscopy    | 53,097           | 58,362             | 10           |

Source: National Cancer Services Analysis Team

2.46 Figure 29 shows the views of Cancer Networks on the main constraints on endoscopy services in their area. Forty seven per cent of Networks told us that lack of trained staff affected endoscopy services in most or all of their hospitals, followed by increases in referrals of non-cancer patients to endoscopy services.

#### Networks' views on impact of endoscopy constraints on their hospitals

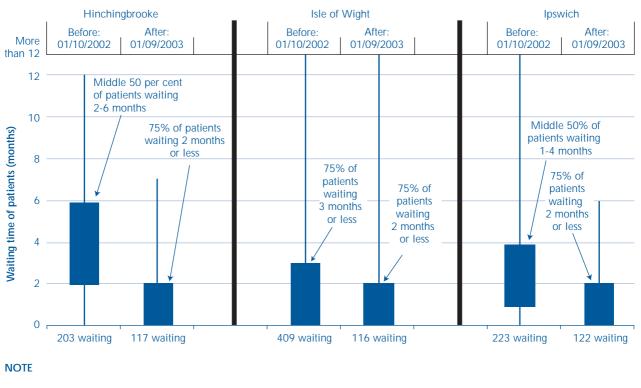


Constraints on endoscopy services that most often affect a large proportion of hospitals in Networks are lack of trained staff and increasing levels of demand from non-cancer patients. Networks did not always know the extent to which some factors were a constraint, even when other networks identified them as a frequent problem.

Source: National Audit Office

- 2.47 Despite the pressures on hospital consultants, relatively little endoscopy is currently carried out in primary care, though there are approximately 30 endoscopy units in primary care. In 2001 and 2002 they were carrying out around 14,000 procedures per unit per year with waiting times of less than one and a half weeks for urgent procedures and less than four weeks for routine procedures. The potential usefulness of such units is shown by the fact that the number of procedures per unit was three times higher than in the late 1990s, although there was very little increase in waiting times<sup>XXXV</sup>.
- 2.48 To address the issue of workforce shortages and to improve the quality of treatment the NHS Cancer Plan made £2.5m available to establish a robust multiprofessional endoscopy training programme which began in September 2001. Almost 500 staff had received some form of training by June 2003. A further £6 million over three years was committed in 2003 to cancer-related training including further expansion of endoscopy training capacity. Three national and 7 regional training centres have been appointed to increase the pool of staff available in hospitals and primary care to carry out gastro-intestinal endoscopies, which would help to identify bowel cancer.
- 2.49 Responsibility for gastro-intestinal endoscopy falls to different teams in different hospitals (for example, gastroenterology and general surgery), or responsibility may be held jointly. The acknowledged result has often been inefficient administrative systems. Because of this, the Modernisation Agency National Endoscopy Programme has produced a toolkit to guide hospitals in redesigning endoscopy services and set up 34 pilot schemes to redesign services.
- 2.50 Figure 30 gives some examples of improvements in waiting times that have resulted. The boxes within the graph represent the time waited by the middle 50 per cent of patients, before and after improvements. The hospitals involved told us that they had achieved these improvements by accurate mapping of capacity and demand (allowing services to be streamlined and justifying additional resources), by more flexible timetabling of sessions and reorganisation and validation of waiting lists, and by raising of the profile of endoscopy amongst NHS Trusts and PCTs through involvement in the Programme.

### 30 Improvements in colonoscopy waits at 3 hospitals



Hospitals that have re-designed services have been able to drastically reduce waiting times and the numbers of those on waiting lists for examination following referral.

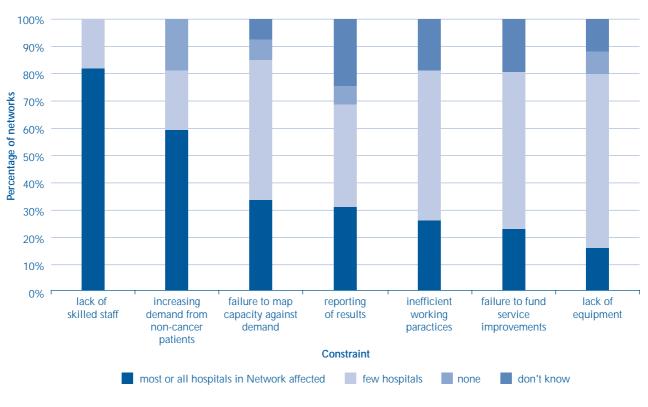
These figures refer to "active" waits, not planned follow-ups.

Source: National Audit Office and NHS Modernisation Agency

There can be long waits for radiological diagnostic procedures, largely due to shortages of skilled staff

- 2.51 Radiological examinations play an important role in the diagnosis of all of the four major cancers. Demand for complex and time-consuming radiology examinations is continuing to increase. Requests for Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) scans increased by 40 per cent and 60 per cent respectively between 1996-97 and 2001<sup>xxxvi</sup>.
- 2.52 It is estimated that approximately one third of CT and MRI scanner use can be attributed to cancer or suspected cancer patients. The Department has acknowledged that waits for the main procedures can be long, although suspected cancer patients should be prioritised. The Audit Commission's comprehensive survey of 253 radiology departments in 2001<sup>xxxvii</sup> found that many radiology departments provided rapid access for patients with suspected breast cancer, 46 per cent of departments for suspected breast cancer, 46 per cent for suspected lung cancer and 47 per cent of departments improved access to their services by taking referrals directly from GPs.
- 2.53 Service Improvement programmes within the NHS now seek to reduce waiting times for all patients by service redesign rather than prioritising some before others. Under the leadership of the Cancer Services Collaborative 'Improvement Partnership', 76 projects have been undertaken by 29 Trusts. In over half of the projects the average waiting times have been reduced to less than 50 per cent. In five projects waiting times have been reduced by 90 per cent or more.
- 2.54 In the view of Cancer Networks responding to our survey (see Figure 31), the main constraints contributing currently to waits for radiological procedures are lack of skilled staff and increasing demand from non-cancer patients for radiology services. Although lack of equipment is not identified as being as significant a Network-wide constraint as other factors, half of Networks had not completed the mapping of capacity and demand for radiology services in late 2003.
- 2.55 There is an overall shortage of diagnostic radiographers and the distribution of diagnostic radiographers per million population varies considerably around the country (see Figure 32). Between 1997 and 2002 the number of diagnostic radiographers employed in the NHS has increased by around 11 per cent to nearly 11,500. However, vacancy rates are also increasing, as the table at Figure 33 shows.

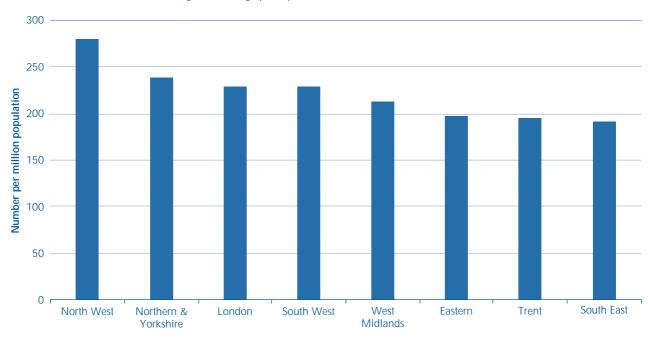
### 31 Networks' views on impact of radiology constraints on their hospitals



Constraints on radiology services that most often affect a large proportion of hospitals in Networks are lack of trained staff and increasing levels of demand.

Source: National Audit Office Survey

### 32 Distribution of diagnostic radiographers by former NHS region (2002)



The South East has one-third fewer diagnostic radiographers per million than the North West.

Source: Department of Health Workforce Survey

### Three Month Vacancy Rates

|                          | Percentage of posts vacant |      |      |      |
|--------------------------|----------------------------|------|------|------|
|                          | 2000                       | 2001 | 2002 | 2003 |
| Diagnostic Radiographers | 3.6                        | 4.4  | 5.5  | 6.1  |

Source: Department of Health Vacancies Survey

The Department is taking steps to improve radiology services by making diagnostic radiography accessible to a broader range of potential recruits, increasing training numbers, re-designing services and purchasing much new equipment

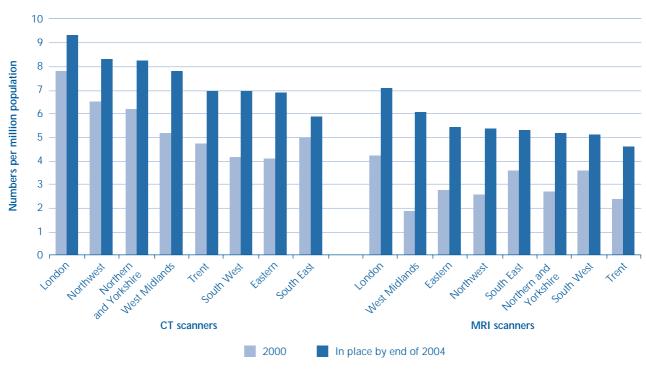
- 2.56 The Department has recognised that radiography workforce issues are critical. A skills mix project was initiated to look into ways of resolving staff shortages, and a new system of staff grades and skills was developed. A four-tier system of grades, is increasingly being adopted by radiography departments<sup>xxxviii</sup>. The Department has also implemented a range of measures to improve the recruitment and retention of NHS staff, including radiographers<sup>xxxix</sup>. As a result of these initiatives over 300 radiographers have returned to work since April 2001 and the number of places available for students to enter training in diagnostic radiography has more than doubled since 1997. The Royal College of Radiologists is working in partnership with the Department of Health and the NHS University to develop a new approach to training radiologists that will allow a significant increase in the number of trainee radiologists without impacting on departments that are already under pressure.
- 2.57 In order to address some of the current constraints on radiology services, the Modernisation Agency has initiated a major programme to streamline radiology services. This included a tool-kit to enable departments to pinpoint bottlenecks in services, and to assist with service redesign to improve efficiency. In June 2003 there were 32 funded radiology project sites working towards service redesign by conducting process-mapping and capacity- and demand-mapping exercises.
- 2.58 Although half of Cancer Networks responding to our survey had yet to complete an analysis of capacity and demand mapping in relation to CT and MRI scanners in late 2003, approximately three quarters of those who had felt that capacity would be sufficient to meet demand once machines allocated to them have been installed. As well as additional scanners, all existing scanners installed before 1996 are due to be replaced by the end of 2006, which will also increase capacity. A recent pan-European study of the age structure of radiology equipment found that of 9 countries, the UK was one of 4 to meet the recommended criteria for age profile of CT scanners and one of 3 to meet the profile for MRI scanners<sup>XL</sup>.

2.59 To some extent the pattern of scanner provision is the result of historic accident and so there are anomalies. However, Figure 34 also shows how the present procurement programme for scanners will provide a more equitable level of provision per million population, especially for MRI scanners. The pattern of provision also has to reflect the importance of demand from non-cancer services.

Shortages of pathology staff can put pressure on the quality of diagnostic services

- 2.60 Histopathologists and cytopathologists (who study the microscopic changes that disease causes in human tissue and cells) play a crucial role as they provide the diagnosis for the vast majority of cancer patients on the basis of tissue and cell samples.
- 2.61 The distribution of histopathologists across Strategic Health Authorities varies widely (see Figure 35 on page 40), which can impose constraints on the speed of diagnosis. The Academy of Medical Royal Colleges recently produced a report stating that "the capacity of most pathology services may be close to or have reached the safe attainable limit.<sup>XLI</sup> "
- 2.62 The total number of consultant histopathologists employed in the NHS increased by 32 percent between September 1997 and June 2003 to a figure of 1,015. Despite this, the vacancy rate for consultant histopathologists increased from 6.4 per cent in 2002 to 7 per cent in 2003.
- 2.63 Pathology suffered from a cut in training numbers in the early 1990s. As a result, the number of registrar (trainee) histopathologists fell from a peak of 332 in 1991 to 168 in 1997, but by 2002 registrar numbers had increased to 289. The number of trainee posts has been boosted by central funding for new posts with 180 new posts being funded between 2002-3 and 2004-5. The NHS has succeeded in recruiting pathologists from overseas.
- 2.64 In line with the commitment in *The NHS Cancer Plan*, three histopathology training schools were established in 2000-01 for Senior House Officers. Funding for the schools has been increased to enable them to take on 24 trainees each year. The initiative is also being extended, increasing the number of schools from 3 to 12 and raising the annual intake from 18 to 96 by 2005-06. Eight exceptional overseas graduates per year are also receiving intensive training to assess competence and educational needs to become specialist registrars.

#### 34 Increase in scanner provision in former NHS Regions



Numbers of scanners are increasing in all areas but imbalances remain between some areas. Since 1997 CT scanner provision will have increased by 89 per cent and MRI scanner provision by 151 per cent.

Source: National Audit Office and Department of Health

2.65 It is essential that the quality of reporting carried out by histopathologists remains high, especially when there are strong pressures to increase throughput. To assist in quality control, an independent, national pathology laboratory accreditation scheme, originally set up by the Royal College of Pathologists is in place. Enrolment in a recognised pathology scheme has been a requirement for all NHS pathology laboratories since June 2003.

### New ways of working are improving the quality of treatments, but speed of access to treatment and its appropriateness continues to be a problem in parts of England

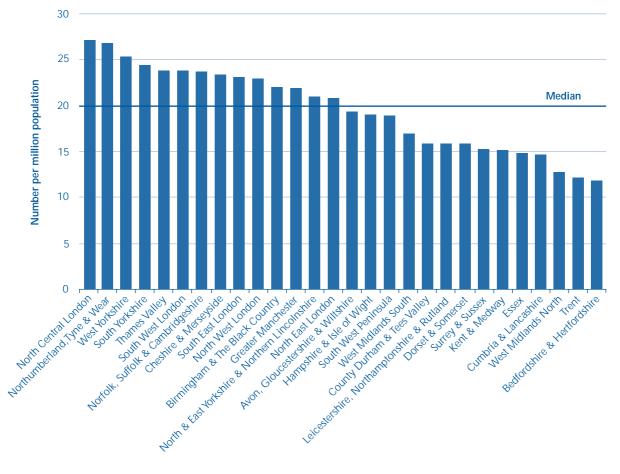
Multi-disciplinary team working is increasingly well embedded in the NHS but is resource intensive

2.66 Multi-disciplinary teams (MDTs) deal specifically with one type of cancer or group of cancers and bring together the relevant professionals with specialised knowledge of diagnosis and treatment including surgeons, radiologists, pathologists, oncologists, nurse specialists and palliative care specialists. A team may cover more than one hospital site if numbers of patients treated are low in particular locations.

- 2.67 MDTs have been well-established in some British hospitals for many years. The technique has also been used at the Institut Gustave Roussy, France's leading cancer centre, since the 1920s. Staff there explained to us how MDT meetings are the foundation for the cancer centre's activities. Staff emphasised to us the value of establishing a consensus about treatment options at these meetings to reinforce good practice and avoid preferences being shown to individual specialisms. They also emphasised that the process made considerable demands on staff time if it is to be done well.
- 2.68 The 1995 Calman-Hine report, and later the 2000 NHS Cancer Plan, called for all cancer treatment in England to be based on such team working. Recent research on Trusts in the Northern and Yorkshire region has shown how team building progressed rapidly, if unevenly, for breast, bowel and lung cancer in the latter half of the 1990s. Breast cancer clinicians were the first to adopt MDT working on a widespread basis in the NHS. The Audit Commission and Commission for Health Improvement cancer review in 2001 established that the practice is now almost universal for the treatment of breast cancer across England<sup>xLii</sup>.

### 35 Number of consultant histopathologists per million population, by SHA (2002)

The Strategic Health Authority (SHA) with the median number of histopathologists has over 50 per cent more such specialists per million population than in the SHA with the lowest number per head.



Source: Department of Health medical and dental workforce survey

- 2.69 The National Peer Review Exercise in 2001<sup>xLiii</sup> recorded that bowel cancer MDTs were better established in some areas than others. Lung cancer MDTs were widely established but under pressure everywhere, primarily because of under-staffing. Networks reported to us that urological cancer MDTs are now also firmly established, although they were not assessed in 2001 as the NICE Improving Outcomes guidance for Urological Cancers had not been issued at that time.
- 2.70 The Audit Commission and Commission for Health Improvement review noted that most MDT meetings took place outside normal working hours due to pressures on staff time. We asked Cancer Networks what constraints still apply to MDTs today. Most mentioned capacity issues - high patient flows and staff shortages leading to key absences and fewer meetings.
- 2.71 Half of the Networks responding to our survey have full administrative support for all major cancer MDTs, but a recurring issue reported to us is the lack of administrative support for MDTs. Support is needed for organising

meetings and the core activity of accurately recording decisions. Post-holders can also carry out the role of managing the progress of patients along the pathway of care (see Appendix 5). Posts can be difficult to fund because of their non-clinical nature, however.

There is increasing specialisation in cancer surgery which will improve outcomes, but there are variations between and within particular cancers

2.72 Improving Outcomes Guidance for different cancers and groups of cancers increasingly reflects research demonstrating that hospitals undertaking larger numbers of cases of complex cancer surgery have produced better results for patients through reduced mortality and morbidity<sup>xt,iv</sup>. This may in part relate to the expertise of surgeons carrying out larger numbers of operations and in part to the expertise of other healthcare staff (such as anaesthetists or nutritionists). This has led to the recommendations in guidance developed by NICE that complex cancer surgery should be concentrated in fewer centres.

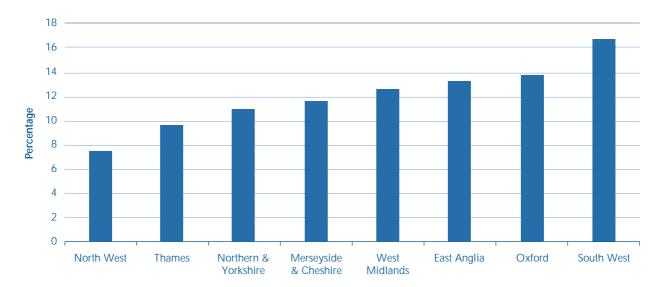
- 2.73 Two thirds of 31 responding Networks told us that all breast cancer patients in their area are now operated on by specialist surgeons. Of the other third, only one said fewer than 90 per cent of patients were. For bowel cancer, of the 19 Networks which were able to answer the question the median proportion of patients operated on by specialist surgeons was 90 per cent, although in one Network the proportion fell to 50 per cent.
- 2.74 Data from cancer registries, see Figure 36, shows wide variations in the level of surgery for non-small cell lung cancer carried out within England. The range of rates of 7 per cent to 17 per cent across the former NHS regions compare with rates of around 25 per cent reported in Holland and the United States. This may reflect a failure to identify cases early enough for them to be operable, the poor general health of patients, or a shortage of thoracic surgeons. A joint working group of the British Cardiothoracic Society and the Society of Cardiothoracic Surgeons reported in 2002 that in order to bring the UK rate of surgery up to the European recommended standard, the number of full-time equivalent thoracic surgeons would have to double to 80. Recent changes in the nature of cardiac work may reduce the workload of cardiothoracic surgeons and help restore the contribution that they can make to thoracic work.
- 2.75 Research shows that better outcomes in prostate cancer surgery are achieved in hospitals where high volumes of prostatectomies (removal of the prostate gland) are carried out each year. In one study the risk of serious complications was 43 per cent greater for hospitals carrying out less than 40 prostatectomies a year than those carrying out 140<sup>xLV</sup>. NICE recommends that ultimately surgery should be carried out by specialist teams carrying out at least 50 radical operations per year, and as an interim measure only surgeons carrying out at least 5 such operations per year (prostatectomies in the case of prostate cancer) should work in this area. 20 Networks out of 21 responding to this question told us that this aim was being achieved for 90 per cent or more of patients.

### Waiting times for radiotherapy treatment can be excessive

2.76 Radiotherapy, involves the use of ionising radiation for the treatment of cancer. Linear accelerators are used primarily for this treatment, although brachytherapy or cobalt machines may also be used. According to the Royal College of Radiologists, the number of exposures delivered in the UK increased by 16 per cent between 1997 and 2002. Demand for radiotherapy services has increased steadily due to:

### 36 Non small cell lung cancer\*: Percentage of cases operated on (diagnosed in 2000)

The regions with higher lung cancer mortality are those with lower surgery rates but it is unclear whether this is the result of differing clinical practice or more advanced cancer at the time of diagnosis in some areas.



### NOTE

\* Small cell lung cancer should only very rarely require surgery if guidance is followed.

Source: UK Association of Cancer Registries and National Audit Office

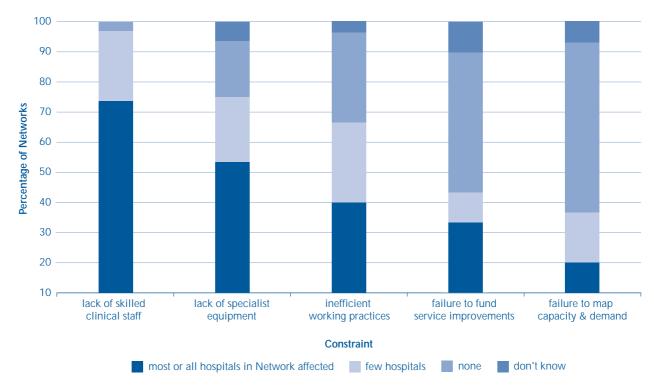
- increases in the incidence of cancer in general (for example due to an ageing population) and higher detection rates of some cancers (especially prostate cancer) for which complex radiotherapy has a major role;
- identification of previously unrecognised need for radiotherapy through improved assessment of patients by multi-disciplinary teams;
- development of new treatments;
- wider application of good practice including a move towards longer courses of treatment (involving more attendances) to reduce the harmful effect of radiotherapy on normal tissues surrounding a cancer; and
- longer survival of patients with advanced disease necessitating more palliative radiotherapy treatment.
- 2.77 The Royal College of Radiologists has evidence-based guidelines on good practice and maximum radiotherapy waiting times, and has carried out a snapshot survey of actual waiting times in 2003, using a standardised definition<sup>XLVI</sup>. The detailed results of this survey were still being analysed as this report was published but they indicate that the situation has not improved since the previous such survey in 1998, with only a minority of patients receiving treatment within recommended waiting times.

2.78 In the view of cancer Networks, see Figure 37 below, the main constraints contributing to waits for radiotherapy are lack of skilled staff and equipment.

The Department is acting to improve radiotherapy services through increased staffing, new equipment and redesign of services

- 2.79 The number of therapeutic radiographers increased by just under ten per cent between 1997 and 2002, to just over 1,540, and the number of consultant clinical oncologists increased by 20 per cent between September 1999 and June 2003, to 367. However, during that period the vacancy rate for therapy radiographers has continued to increase, see figure 38.
- 2.80 The Department has recognised that radiotherapy workforce issues are critical. A skills mix project was initiated to look into ways of resolving staff shortages, and a new system of staff grades and skills was developed. A four-tier system of grades, is increasingly being adopted by radiography departments<sup>xLvii</sup>. The Department has recently announced £3 million of funding to boost the number of radiographers working in the NHS. A recruitment and retention strategy has been developed to encourage returners to the profession and develop better career pathways for radiographers<sup>xLviii</sup>.

### 37 Networks' views on the impact of radiotherapy constraints on hospitals in their Network



Constraints on radiotherapy services that most often affect whole Networks are lack of trained staff and lack of specialist equipment.

Source: National Audit Office Survey

### Three Month Vacancy Rates

|   | Percentage of posts vacant |      |      |      |
|---|----------------------------|------|------|------|
|   | 2000                       | 2001 | 2002 | 2003 |
| Therapeutic Radiographers                     | 7.1                        | 8.0  | 8.8  | 10.7 |
| Source: Department of Health Vacancies Survey |                            |      |      |      |

The number of training places also increased by 111 per cent between 1997 and 2002.

- 2.81 More linear accelerators are being purchased to address lack of specialist equipment and meet demand. A figure of four machines per million was considered an appropriate figure by the Royal College of Radiologists at the time of the Cancer Plan though continued increases in workload have led the Royal College of Radiologists to recommend five machines per million by 2006<sup>xLix</sup>. By the end of 2004 it is projected that there will be 215 linear accelerators in the NHS in England (4.4 per million population), an increase from 140 in 1997. In addition, by December 2006, no linear accelerators should be older than 11 years. Ten of the 22 Cancer Networks in our survey who had mapped capacity and demand for radiotherapy by late 2003 told us that when allocated machines were installed, the number of linear accelerators would be sufficient to meet demand.
- 2.82 The Cancer Services Collaborative Improvement Partnership is already running "improvement programmes" in around 35 of the 53 radiotherapy departments in England to remove bottlenecks in the patient care pathway for radiotherapy. It is too soon to evaluate the overall effectiveness of this programme.

Concerns remain that chemotherapy and other systemic therapies are not available equitably across England

- 2.83 Over the past few years there has been a marked increase in the use of systemic therapies such as chemotherapy and hormonal therapy for cancer, and novel treatments which target specific molecular abnormalities within cancer cells. Systemic therapies for cancer can be used as curative treatments on their own, as adjuncts to surgery and radiotherapy or as treatments for incurable cancer given with the aim of prolonging life and improving quality of life.
- 2.84 The 2001 National Peer Review exercise established a national picture of considerable variations in the quality of chemotherapy services with some areas operating at capacity and responding reactively to service pressures. There were also some concerns about the safe environment for the delivery of chemotherapy.

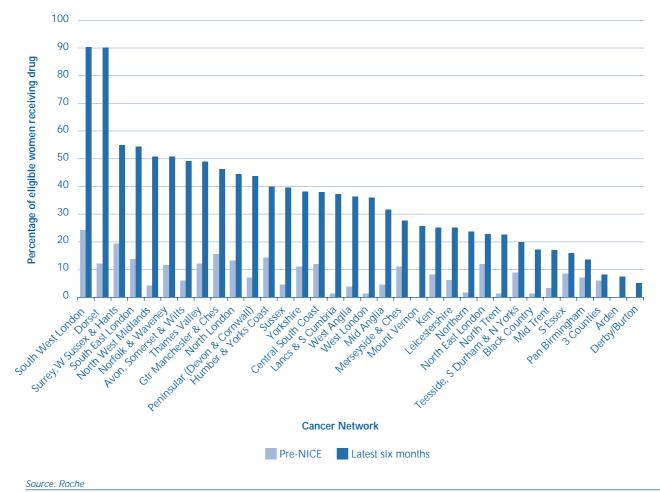
- 2.85 In the late 1990s concerns were expressed regarding variations in funding for licensed chemotherapy drugs across the country. The National Institute for Clinical Excellence (NICE) was set up in part to eliminate the so-called "postcode lottery" of drugs. Cancer drugs that are positively appraised by NICE should be prescribed to patients whenever clinically appropriate, with funding being made available by Primary Care Trusts within 3 months of a positive appraisal. The large majority of the cancer drugs assessed by NICE have been approved for use within the NHS. Consequently, according to information supplied by various pharmaceutical companies to the National Cancer Director, overall usage of these drugs has increased markedly as a result of this.
- 2.86 Concerns remain however that wide variations in usage persist between different parts of the country. An illustration of such geographical variations is provided by data supplied by Roche relating to the use of *Herceptin*. The drug was approved for use by NICE in March 2002 as a treatment for women suffering from metastatic breast cancer who have a tumour expressing an excess of a particular protein.
- 2.87 Figure 39 shows the impact of NICE approval on *Herceptin* prescribing. By 18 months after NICE approval, the median Network had five times the proportion of eligible patients on Herceptin compared with the period prior to NICE approval. Nevertheless, the range of eligible women receiving the therapy ranged across individual Networks from almost all women to almost none. The Secretary of State for Health has asked the National Cancer Director to look at the variation in uptake of NICE approved cancer drugs across the country and take action if unacceptable variation is found.
- 2.88 Figure 40 shows the distribution of qualified oncologists, both clinical and medical, who prescribe chemotherapy. In the past, the absence of approved prescribing protocols has led to variations in the levels of prescribing around the country. Twenty three out of 29 Networks told us that Network-wide protocols for systemic therapies are now in place to encourage standardisation in prescribing practice. The Department of Health is starting a national review of chemotherapy.

### Access to treatments varies between different groups

2.89 It has been observed in many countries that patients diagnosed with the same cancer at the same stage of development do not necessarily receive the same treatment. Much of this is due to "co-morbidity" - the extent to which adverse factors such as the existence of other diseases and poor diets, tobacco consumption and less exercise render people less physically able to face - or survive - radical treatment<sup>L</sup>.

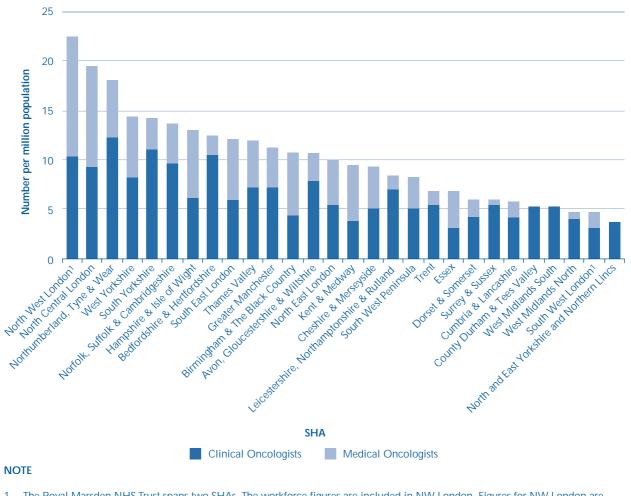
### 39 Variations in the percentage of eligible cancer patients receiving Herceptin in the 6 months before NICE approval (October 2001- March 2002) and 12 to 18 months afterwards (April-September 2003)

Proportion of eligible women receiving the treatment has increased, on average, 500 per cent - but the increase is not uniform across England.



- 2.90 Research on co-morbidity has established that higher co-morbidity is associated with increased deprivation<sup>Li</sup>. Co-morbidity also increases with age, and particularly affects males and those with tobacco-related tumours. However, co-morbidity may not explain all treatment variations for the deprived. For example, research identified that women from deprived areas undergo much higher proportions of mastectomies (breast removal) rather than breast conservation surgery<sup>Lii</sup>. Whether geographical and socio-economic inequalities in treatment are due to discrimination, patient preference, patient delay in presentation or co-morbidity remains unclear<sup>Liii</sup>.
- 2.91 A particular group which often receives less intensive treatment for cancer are older people. Since older people are more likely to suffer co-morbidity, there may be good reasons for less intensive treatment. Nevertheless, the existence of age discrimination generally in health and social care was acknowledged by the National Service Framework for Older People, published in 2001. It made clear that treatment should not be determined by age but by individual needs and priorities of the person. Steps have been taken to address this, notably the establishment of a network of "Champions" to promote services for older people. It is not possible currently, however, to analyse how the NHS as a whole is treating older cancer patients because data on the overall severity of their illness and nature of their treatment, taking into account comorbidity, are not available.

### 40 Qualified consultants prescribing chemotherapy and associated treatments by SHA (2002)



Distribution of clinical and medical oncologists varies considerably across England.

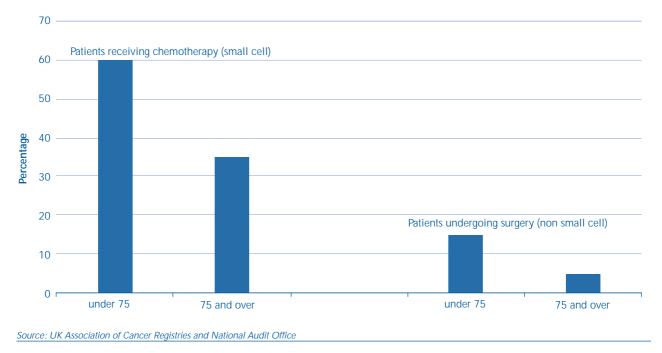
1 The Royal Marsden NHS Trust spans two SHAs. The workforce figures are included in NW London. Figures for NW London are artificially high and for SW London are artificially low.

Source: Department of Health medical and dental workforce Survey

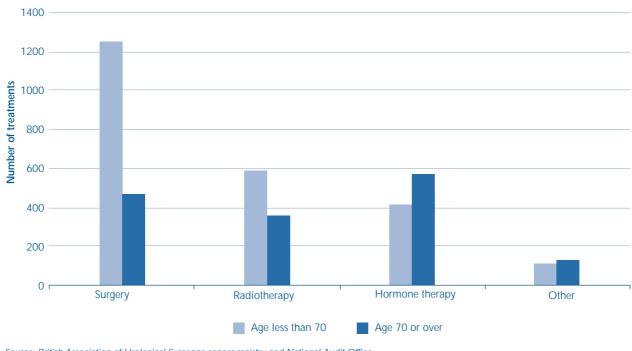
- 2.92 Figure 41 shows the sharp reduction in chemotherapy usage and surgery for both types of lung cancer, smallcell and non-small-cell, for patients over the age of 75 covered by eight English cancer registries. A study by the Northern and Yorkshire Cancer Registry in 1999 found that different approaches for older people start before decisions on treatment. While 89 per cent of lung cancer patients under the age of 65 were managed by a specialist, only 53 per cent of those over 75 were<sup>Liv</sup>. Specialist care produced higher one and two-year survival rates for recipients than non-recipients. Recent research has identified a reluctance to carry out extensive diagnostic testing and active treatment in older people with lung cancer even if they did not exhibit any other obvious health-related problems<sup>LV</sup>.
- 2.93 Another example of these age-related differences in the intensity of treatment given is information from the British Association Of Urological Surgeons database showing that prostate cancer patients over the age of 70 receive much less radical treatment for early stage cancer than their younger peers (see Figure 42).
- 2.94 The National Clinical Audit Support Programme, commissioned by the Commission for Health Improvement and operated by the NHS Information Authority, is working with representative bodies of the relevant health professionals to provide an on-going assessment to review clinical practice and the delivery of care. These assessments cover breast, lung, bowel and head and neck cancer and may provide an insight into the underlying reasons why certain groups receive different treatment.

### 1 Access to treatment for lung cancer patients diagnosed in 2000 varies with age

Lung cancer patients over the age of 75 are much less likely to receive chemotherapy or undergo surgery.



### 42 Pattern of treatment given to prostate cancer patients diagnosed in 2002 with PSA score of 0-10 varies with age



Prostate cancer patients over the age of 70 with a PSA score of less than 10 receive much less radical treatment despite the fact that nearly 90 per cent of tumours with this PSA score were staged as not having spread beyond the prostate.

Source: British Association of Urological Surgeons cancer registry and National Audit Office

# Glossary

| Barium meal   | An x-ray examination of the stomach and gullet facilitated by radio-opaque material taken orally.   |
|---|---|
| Brachytherapy   | A way of delivering radiotherapy (qv) to some cancers (including prostate cancer) through implants which releases radiation slowly over time.   |
| Bronchoscopy  | An endoscopic (qv) examination to check the airways of the lungs.   |
| Calman-Hine report  | 1995 report establishing a framework for the future delivery of cancer services by primary care, Cancer Units and Cancer Centres (see Appendix 1).  |
| Cancer Services Collaborative<br>(CSC) Improvement<br>Partnership | The CSC's Improvement Partnership is a national programme to develop practical approaches to deliver the targets in the NHS Cancer Plan and is part of the NHS Modernisation Agency (see Appendix 1). |
| CancerBACUP   | Charity which has offered a national cancer information service since 1985.   |
| Cardiothoracic surgery  | Surgery on the heart, chest and lungs.  |
| Chemotherapy  | The use of anti-cancer drugs to destroy cancer cells.   |
| Clinical Trial  | Medical research involving patients to identify new and better treatments.  |
| Cobalt machines   | Machine for delivering radiotherapy (qv) treatment, now being superseded by linear accelerators (qv).   |
| Colonoscopy   | An endoscopic (qv) examination to check for bowel cancer, among other conditions.   |
| Coloproctology  | The study and treatment of diseases and disorders affecting the colon, rectum and anus.   |
| Computerised Tomography<br>(CT)                                   | A radiographic (qv) technique that uses a computer to assemble x-rays into a cross-<br>sectional image of a person.   |
| Consultant  | Senior physician or surgeon advising on the treatment of a patient.   |
| Deprivation   | Being economically disadvantaged. Deprived areas are identified by using one of several available indices related to lower income.  |
| Diagnostic test   | Test or procedure to determine the cause of an illness or disorder.   |
| Endoscopy   | The inspection of any cavity within the body using a flexible tube with a light source.   |
| General Practitioner (GP)   | A doctor who practices general medicine in the community.   |
| Linear accelerator  | A machine for delivering radiotherapy (qv) by focusing a beam of radiation onto the affected area, more accurately than cobalt machines (qv).   |
| Magnetic Resonance Imaging<br>(MRI)                               | A technique to image the internal tissues and organs of the body using magnetic fields, providing greater detail than a conventional x-ray.   |
|   |   |

| Melanoma                                     | A cancer which starts in the skin.   |
|--|--|
| National Clinical Audit<br>Support Programme | A programme being developed in co-operation with representative bodies of the relevant health professionals and operated by the NHS Information Authority (see Appendix 1), with the aim of developing an on-going assessment to review clinical practice and the delivery of care for a number of cancers and other conditions.                 |
| Oncologist                                   | A doctor who specialises in the diagnosis, treatment and rehabilitation of people with cancer. A clinical oncologist is trained in the use of radiotherapy (qv) and chemotherapy (qv). A medical oncologist specialises in chemotherapy treatment.   |
| Palliative care                              | Treatment aimed at relieving symptoms and pain rather than effecting a cure.   |
| Pathology                                    | The study of the causes and effects of disease by examining changes on tissues and cells.  |
| Peer Review exercise                         | National exercise in 2001 to assess the quality of services against NHS cancer standards (to be repeated in 2004).   |
| Primary care                                 | The organisation and provision of healthcare within the community rather than in the hospital.   |
| Prostate Specific Antigen<br>(PSA) Test      | The test measures the level of the Prostate Specific Antigen (a protein) in the blood.<br>A minority of men with a raised PSA level will be diagnosed with prostate cancer.  |
| Radiographer                                 | A non-medically qualified healthcare professional. Diagnostic radiographers are responsible for taking (and sometimes interpreting) images of the body - including conventional x-rays, CT scans and MRI scans (qv). Therapy radiographers work in radiotherapy departments and operate radiotherapy equipment such as linear accelerators (qv). |
| Radiology                                    | The use of X-rays to diagnose a disease.   |
| Radiotherapy                                 | The treatment of disease by radiation.   |
| Registrar                                    | A hospital doctor junior to a consultant (qv).   |
| Screening                                    | Examination of people with no symptoms to detect disease. In England there are national screening programmes for breast and cervical cancer.   |
| Senior House Officer                         | A doctor junior to a registrar (qv) or a consultant (qv).  |
| Specialist                                   | Someone devoted to the care of a particular part of the body, or a particular aspect of diagnosis, treatment or care.  |
| Stage  | The extent to which cancer has spread from its original site to other parts of the body.<br>Usually numbered from stage 1 (least advanced) to stage 4 (most advanced).   |
| Systemic therapies                           | Treatment that reaches and affects cells all over the body.  |
| Thoracic surgeon                             | A surgeon expert in the treatment of diseases of the chest and lungs.  |
| Urological cancer                            | Term covering prostate, testicular, penile, kidney and bladder cancer.   |

## Appendix 1 Key stakeholders involved in cancer services

| Stakeholder                                       | Role  |
|---|---|
| National  |   |
| Department of Health                              | Setting overall policy direction, securing resources and setting national standards.  |
| National Cancer Director                          | Takes the lead in developing and implementing the Department's strategy for cancer.<br>He is supported by the <b>Cancer Action Team</b> , the Department's cancer policy team and<br>the CSC Improvement Partnership.   |
| NHS Cancer Screening<br>Programme                 | Oversees the delivery of screening programmes for breast (in over 90 units) and cervical cancer, and the development of screening programmes for other cancers.   |
| Care Group Workforce Team:<br>Cancer              | Draws up national workforce strategies for cancer. It is supported by the <b>lead Workforce</b><br>Development Confederation.   |
| NHS Information Authority                         | Develops information services to support the key clinical priorities of the Department of Health, including development of the national cancer dataset to provide data on the whole cancer care pathway, waiting times and support for the National Clinical Audit Support Programme.                                 |
| Modernisation Agency                              | Supporting the NHS and its partner organisations in improving cancer services. It aims to achieve this through the <b>individual projects within the Cancer Services Collaborative Improvement Partnership</b> and the <b>National Booking Programme for endoscopy</b> .  |
| Cancer registries                                 | 9 regional cancer registries collect and collate data from their area and report the results to the Office for National Statistics.   |
| Office for National Statistics                    | The <b>National Cancer Intelligence Centre</b> at the ONS collates national cancer data and carries out a range of research. It publishes definitive data on cancer outcomes in England.  |
| Commission for Healthcare<br>Audit and Inspection | Will succeed the <b>Commission for Health Improvement</b> from 1 April 2004, but continue its role of independently inspecting service standards for cancer patients, among others. It will commission national clinical audits of cancer-related subjects.   |
| National Institute for<br>Clinical Excellence     | Providing patients, health professionals and the public with authoritative, robust and reliable guidance on current "best practice". It is responsible for producing cancer Improving Outcomes Guidance and assessing the clinical- and cost-effectiveness of new treatments and promoting their adoption by the NHS. |

| Stakeholder                  | Role   |
|------------------------------|--|
| Local                        |  |
| Cancer Networks              | The organisational model to deliver the Cancer Plan at a local level. There are 34, bringing together commissioners and providers of cancer services from the NHS, local authorities and the voluntary sector.                               |
| Strategic Health Authorities | 28 SHAs manage the performance of NHS services locally and develop local plans to meet national priorities.  |
| Primary Care Trusts          | Commissioning the majority of NHS services and managing the provision of cancer services in the community.   |
| Cancer units                 | Normally a district hospital, offering a range of diagnostic and treatment services and care for patients with the commoner cancers. Cancer units are not separated from other hospital services but are an integrated part of the hospital. |
| Cancer centres               | Normally part of a large general hospital, providing services for patients with commoner cancers, as well as an additional range of specialised services which it will normally provide in support of cancer units.                          |
| Service users                | Service users (patients and carers) are increasingly seen as stakeholders in cancer services who can contribute to the planning, development and implementation of cancer services.  |

## Appendix 2

Methodology

1 We adopted a variety of methods to collect evidence to assess the progress in improving cancer outcomes by the NHS. These are summarised below:

### Analysis of outcomes data for England and other countries

- 2 We used the following data sources:
  - The most up-to-date information on English cancer incidence, mortality and survival, came from analysis of published and unpublished data produced by the Office for National Statistics National Cancer Intelligence Service. The most comprehensive published source of such data is: Quinn MJ, Babb PJ, Brock A, Kirby EA, Jones J. Cancer Trends in England and Wales, 1950-1999. Studies on Medical and population Subjects No.66 (London: The Stationery Office, 2001);
  - Information on international comparisons of survival rates came from the second and third studies on European cancer survival produced under the auspices of the EUROCARE Working Group in 1999 and December 2003 respectively, covering patients diagnosed between 1985 and 1994; and
  - Information on international comparisons of mortality rates came from the mortality database maintained by the World Health Organisation Information System. We compared data from 1994, the last year before the Calman Hine report began the reorganisation of NHS cancer services, and 1998, the last year for which most countries have submitted data.

## Analysis of other cancer data produced by the NHS and others

- 3 On our behalf Professor David Forman and Dr Diane Stockton from the UK Association of Cancer Registries analysed data on 72,000 breast, bowel and lung cancers registered in 2000 to examine variations in treatment and patient demographics in different geographical areas. Registries use different methodologies for data collection so this sort of comparative analysis had not previously been done. As a result we have been conservative in our use of the data and avoided unreliable comparisons. It should be noted that registries are dependent on the availability of treatment information in clinical notes and on treatment centres making these available.
- 4 We also used data from a range of other organisations, such as the Cancer Services Collaborative Improvement Partnership, and cancer datasets from professional organisations such as the British Association of Urological Surgeons.
- 5 We gathered data on endoscopy waiting times from participants in the Modernisation Agency endoscopy programme, following problems with the Agency's data collection software.
- 6 In the absence of regular data collection on chemotherapy treatment take-up within the NHS, Roche provided us with data on the market penetration of several of their front-line systemic therapy treatments. They use a methodology agreed with the National Cancer Director.
- 7 The Royal College of Radiologists provided us with an advance view of results from their five-yearly comprehensive survey of radiotherapy waiting times, although the detailed analysis was not completed in time for inclusion in this report.

### Surveys of GPs and consultants

- 8 We commissioned Doctors.net to circulate an electronic survey to their several thousand GP subscribers. This sought their views on referring patients with possible cancer symptoms and their interaction with hospitals, as well as subjects relevant to our other cancer studies. 814 respondents successfully completed the survey within our timescale. Unfortunately the response rate was reduced by automatic rejection of a large number of partially completed responses. Findings are therefore indicative rather than fully representative.
- 9 We commissioned Mercator to carry out a survey of 163 lung consultants (respiratory physicians) and 167 bowel consultants (those within the general surgery specialty who expressed a specific area of interest in coloproctology and colonoscopy) randomly selected from consultant lists on the Dr. Foster web-site. This established workload and the quality of referrals they receive from primary care (of the 4 commonest cancers, lung and bowel are the two with the lowest survival rates). There are some 530 respiratory physicians. The number of general surgeons specialising in bowel work is not known. 94 lung and 81 bowel consultants responded within our timescale. Some 8,000 patients were diagnosed with cancer in the previous 6 months under their supervision.

### Survey of Cancer Networks

10 We surveyed the 34 NHS cancer Networks on behalf of all three studies to establish their level of oversight of cancer services in their locality and their views on the state of cancer services locally, including the spread of best practice in surgical treatment and the constraints facing key diagnostic services. We received responses from 31 of 34 Networks in time for inclusion in this report. The Networks that did not respond were: Humber and Yorkshire Coast, North West Midlands and West Anglia.

### Literature reviews and existing research

11 We reviewed and analysed existing departmental and official publications and a large body of academic research on clinical issues. We are very grateful to Professor Michel Coleman of the London School of Hygiene and Tropical Medicine for allowing us to access his latest research on cancer survival in advance of publication.

### Interviews with NHS bodies and third parties

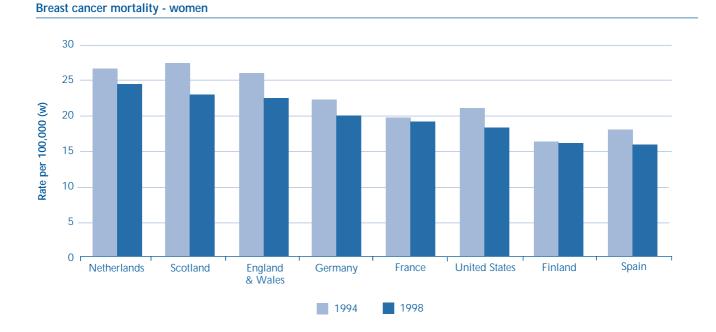
- 12 Throughout the study we undertook interviews with: the National Cancer Director and members of his team and Cancer Networks; project managers and clinical leads involved in NHS Modernisation Agency service improvement projects; representatives of professional bodies involved in treatment and clinical research; statisticians; and had follow-up meetings with Department of Health policy staff.
- 13 We visited Paris and Lille to gather the views of leading clinicians and evaluators of cancer services to compare their experience with that of England.

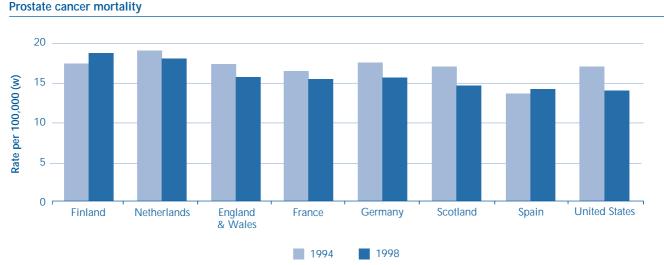
### Reference panel

- 14 We formed a joint reference panel for all three cancer studies to provide feedback on our proposed approach and initial findings. The members are:
  - Mary Barnes, Avon, Somerset and Wiltshire Cancer Services;
  - Mitzi Blennerhassett, former cancer patient and participant in a number of patient advocacy and support groups;
  - Dr Peter Clark, Clatterbridge Centre for Oncology and Association of Medical Oncologists;
  - Stephen Dunmore, New Opportunities Fund;
  - Dr John Ellershaw, Marie Curie Centre;
  - Professor David Forman, Northern & Yorkshire Cancer Registry and Information Service;
  - Martin Ledwick, CancerBACUP;
  - Dr Fergus Macbeth, Velindre NHS Trust and Clinical Effectiveness Support Unit (Wales);
  - Dame Gill Oliver, Macmillan Cancer Relief;
  - Professor Mike Richards, National Cancer Director;
  - Professor Alison Richardson, Florence Nightingale School of Nursing and Midwifery;
  - Peter Tebbit, National Council for Hospice and Specialist Palliative Care Services;
  - Jill Turner, Cancer Services Collaborative Improvement Partnership; and
  - Julie Wood, South Leicestershire PCT.

# Appendix 3 International comparisons of mortality rates for the four major cancers

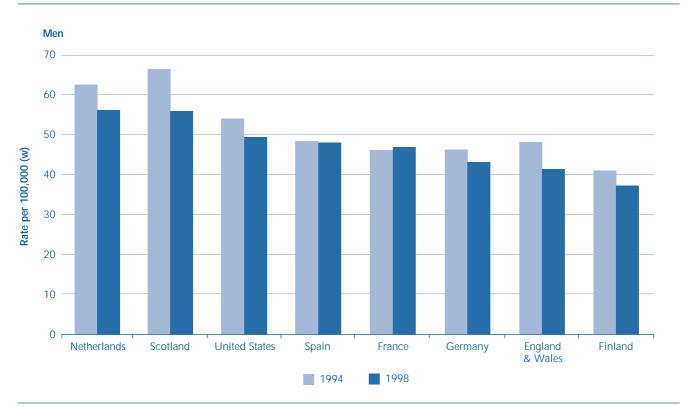
- 1 The source for all of the data in this Appendix is the cancer mortality database drawn from the World Health Organisation Statistical Information System. We used mortality data for comparable countries from 1994 (the last year before the Calman-Hine report started the re-organisation of English cancer services) and 1998 (the most recent year for which most countries have submitted data). Some countries have been omitted because their populations were too small or their data too old.
- 2 Mortality rates for men in England and Wales in 1998 were lower for lung cancer than for most other countries but less so for prostate cancer. Cancer mortality rates among women in England and Wales for intestinal cancer are closer to the best countries than for lung or breast cancer.

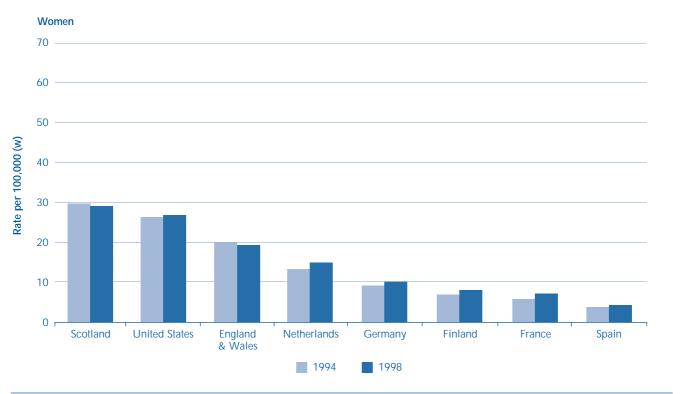




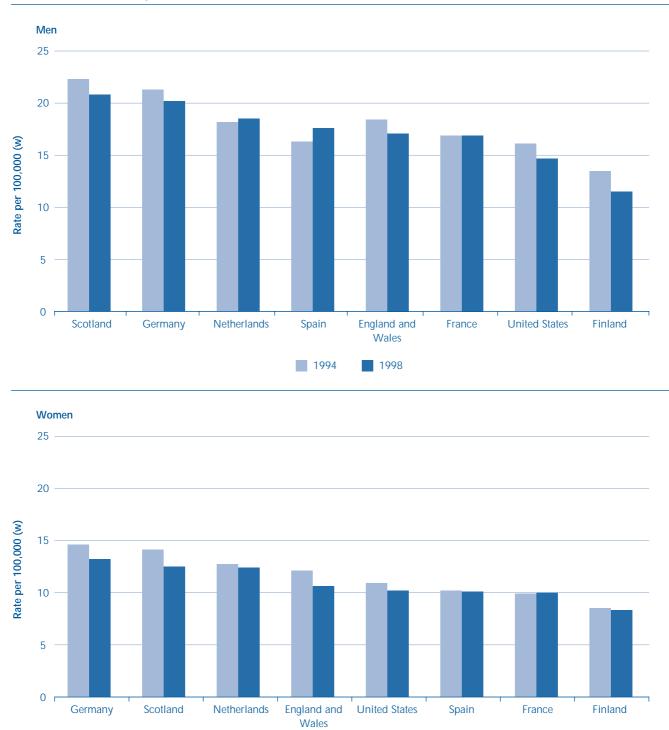
appendix three

### Lung cancer mortality









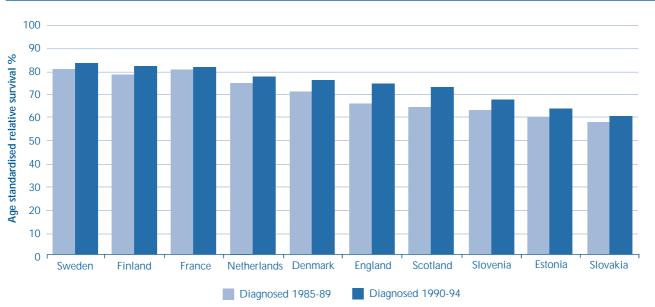
1994

1998

## Appendix 4

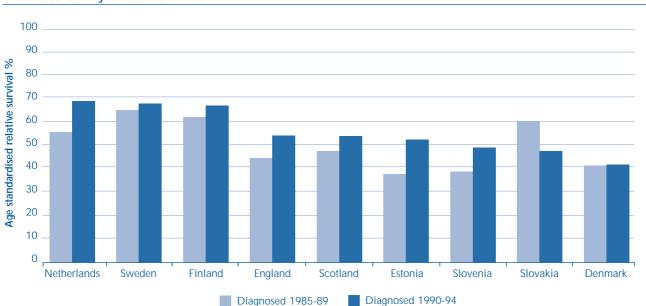
International comparisons of relative survival rates for the four major cancers

1 All of the data in this Appendix is drawn from the EUROCARE-2 and EUROCARE-3 Studies: Berrino et al (eds). Survival of Cancer Patients in Europe: the EUROCARE-2 Study (IARC Scientific Publications No. 151). Lyon, France: IARC 1999; and Berrino et al (eds). Survival of Cancer Patients in Europe: the EUROCARE-3 Study. Annals of Oncology 2003: 14 (Supp 5).



### Breast cancer 5-year relative survival

### NOTE

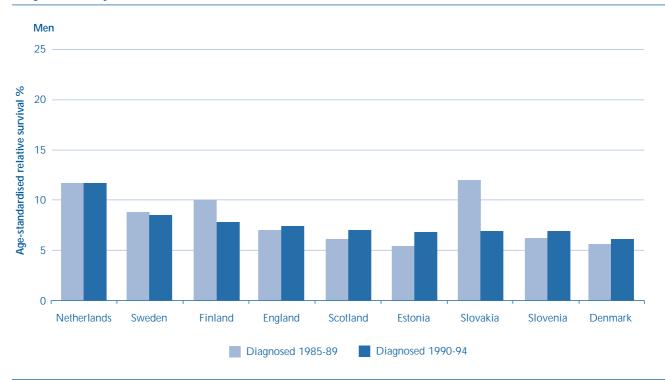


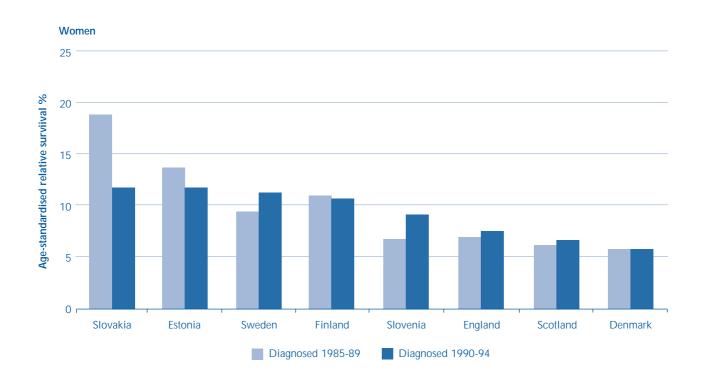
### Prostate cancer 5-year relative survival

French data is included here as data is collected more widely for breast cancer than other cancers.

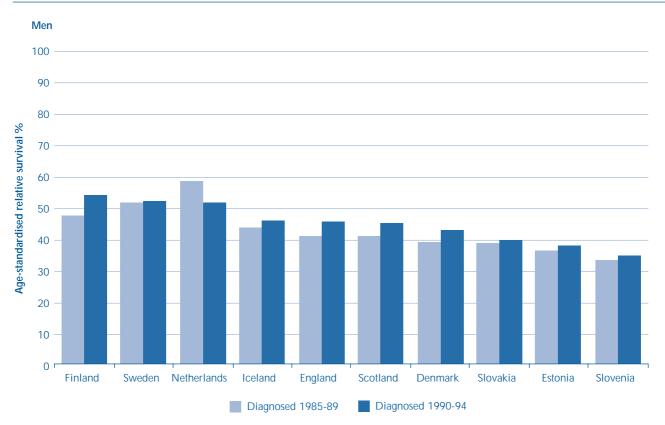
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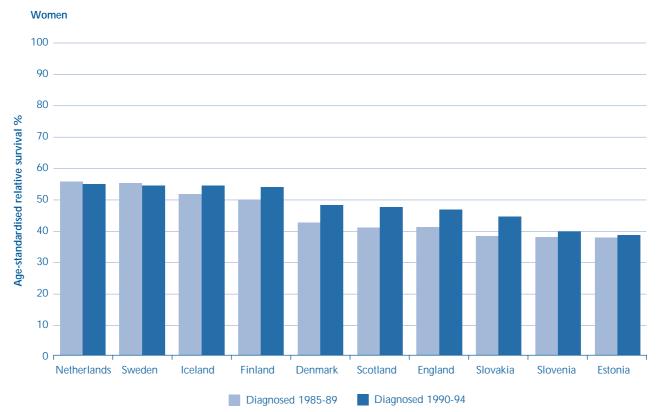








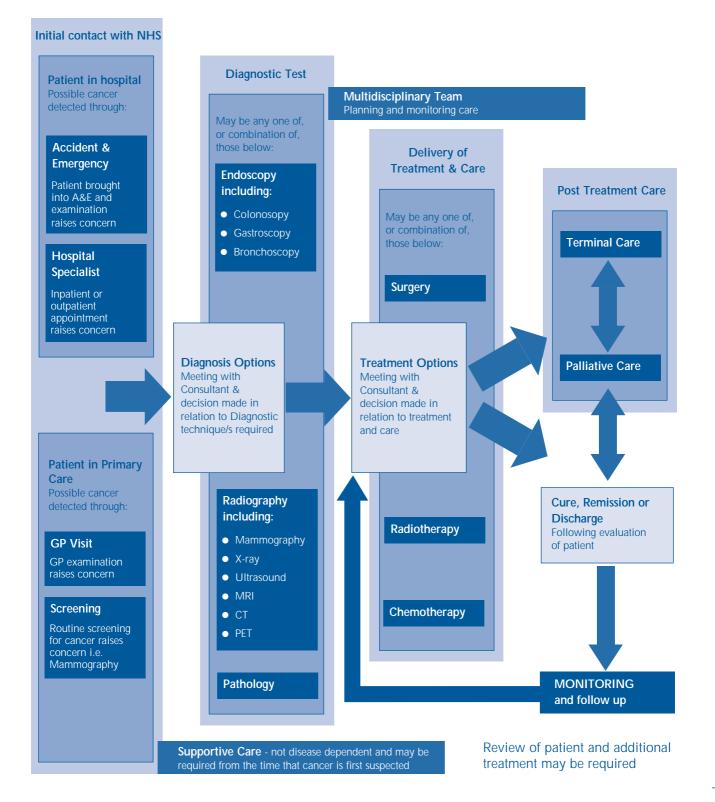




### NOTE

1. Figures given for colon, since figures for bowel (colon and rectal) cancer not available in the EUROCARE 2 study.

## Appendix 5 The cancer patient care pathway



## References

| i     | All incidence figures in this report exclude non-melanoma skin cancers. These conditions are widely under-<br>registered because they depend greatly on a registry's degree of access to out-patient and GP records.   |
|-------|--|
| ii    | Smoking Kills: A white paper on tobacco. Cm 4177 (1998).   |
| iii   | The major source of information on incidence, mortality and survival in England was the Office for National Statistics, for international comparisons on survival rates the EUROCARE studies, and for international comparisons of mortality rates the World Health Organisation Information System. |
| iv    | Coleman et al. Trends and socio-economic inequalities in cancer survival in England and Wales up to 2001.<br>British Journal of Cancer [in press for March 2004].  |
| V     | West Midlands Cancer Intelligence Unit. Cancer and deprivation (2002).   |
| vi    | International mortality data for bowel cancer groups together cancer of the large (colon and rectum) and small bowel. The number of cases of the latter are very small by comparison with the former.  |
| vii   | SEER Cancer Statistics Review, 1975-2000. National Cancer Institute (2003). Mortality rates for these areas are about 5 per cent lower than for the USA as a whole, but populations are representative of the rest of the USA in terms of poverty and education.                                     |
| viii  | Sant et al. Breast carcinoma Survival in Europe and the United States. Cancer 2004; 100 : 715-722.   |
| ix    | Sant et al. Stage at diagnosis is a key explanation of differences in breast cancer survival across Europe.<br>International Journal of Cancer 2003; 106 : 416-422.  |
| х     | A Policy Framework for Commissioning Cancer Services: a report by the expert advisory group on cancer to the Chief Medical Officers of England and Wales (1995).   |
| xi    | The NHS Cancer Plan: a plan for investment, a plan for reform. Department of Health (2000).  |
| xii   | The NHS Cancer Plan: three year progress report -maintaining the momentum. Department of Health (2003).  |
| xiii  | HM Customs and Excise. Measuring and Tackling Indirect Tax Losses - an update of the Government's strategic approach (2003).   |
| xiv   | Peto et al. Smoking, smoking cessation, and lung cancer in the UK since 1950: combination of national statistics with two case-control studies. BMJ 2000: 323-329.   |
| XV    | Chesterman et al. How effective are smoking cessation services in reaching smokers in disadvantaged areas in England? Addiction 2004. In press.  |
| xvi   | Barlow. Evaluation of Smoking Cessation Cancer Plan Projects Targeting Manual Workers.   |
| xvii  | Department of Health. The Health of Minority Ethnic Groups, Health Survey for England 1999.  |
| xviii | Blanks et al. Effect of NHS Breast Cancer Screening Programme on Mortality from Breast Cancer in England and Wales, 1990-8: Comparison of Observed with Predicted Mortality. BMJ 2000:665-669.   |

| xix    | Threlfall et al. Impact of NHS breast screening on advanced disease and mortality from breast cancer in the North West of England. British Journal of Cancer 2003; 89: 77-80.   |
|--------|---|
| xx     | Radiography Skills Mix - A report on the four-tier service delivery model. Department of Health (2003).   |
| xxi    | Alexander and Weller. Evaluation of the UK Colorectal Cancer Screening Pilot. Available at http://www. cancerscreening.nhs.uk/colorectal/pilot-evaluation.  |
| xxii   | Quinn. International comparisons of cancer survival. Health Statistics Quarterly 6. Office for National Statistics (2000).  |
| xxiii  | Richards et al. The influence on survival of delay in the presentation and treatment of symptomatic breast cancer.<br>British Journal of Cancer 1999; 75(5/6): 858-864.   |
| xxiv   | Cancer and Deprivation 2002. The West Midlands Cancer Intelligence Unit.  |
| XXV    | Richards et al. The influence of delay on survival in patients with breast cancer: a systematic review. Lancet 1999; 353:1119-1126.   |
| xxvi   | Omnibus survey carried out for Breast Cancer Care's 80 over 50 campaign.  |
| xxvii  | Yardley et al. Demographic factors associated with knowledge of colorectal cancer symptoms in a UK population-based survey. Annals of the Royal College of Surgery in England 2000; 82(3); 205-9.   |
| xxviii | Opinion poll carried out for the Institute of Cancer Research's everyman campaign.  |
| xxix   | Mackie et al. Effect of public education aimed at early diagnosis of malignant melanoma: cohort comparison study. BMJ 2003; 326:367. Marks. Campaigning for melanoma prevention: a model for a health education program. Journal of the European Academy of Dermatology and Venereology; 2004; 18(1): 44-7. |
| ххх    | Spurgeon & Barwell. Cancer waiting times audit: Final Report. HSMC, University of Birmingham, 1999.   |
| xxxi   | Thompson et al. Identifying and managing patients at low risk of bowel cancer in general practice. BMJ 2003; 327:263-265.   |
| xxxii  | Information on performance against targets is available at www.performance.doh.gov.uk/cancerwaits.  |
| xxxiii | Selvechandran et al. Prediction of colorectal cancer by a patient consultation questionnaire and scoring system: a prospective study. Lancet 2002; 360: 278-83.   |
| xxxiv  | Bowles et al. A prospective study of colonoscopy practice in the UK today: are we adequately prepared for national colorectal screening tomorrow? Gut 2004; 53: 277-283.  |
| XXXV   | Gibson. Report from Community Endoscopists' Unit, 8th Annual Endoscopists' Symposium (2003).  |
| xxxvi  | Audit Commission. Acute hospital portfolio review of national findings: radiology. July (2002).   |
| xxxvii | ibid.   |

| xxxviii | The four tier structure is a model that enables clinical career development beyond the traditional clinical grading that  |
|---------|---|
|         | exists. The 4 tiers equate to levels 4-8 of the career framework that determine pay bands. Level 4 is the Assistant Practitioner who performs protocol-limited clinical tasks under the direction and supervision of a state-registered practitioner - this is a completely new role. Levels 5 and 6 are state registered radiographers (practitioner) who have a wide ranging and complex clinical role. Level 7 is an Advanced Practitioner level who is autonomous in clinical practice and defines the scope of practice of others. Level 8 is Consultant Practitioner who provides clinical leadership within the specialism, bringing strategic direction, innovation and influence through practice, research and education. |
| XXXIX   | These include improving pay and conditions, increasing the number of students entering training, encouraging the NHS to become a more flexible and diverse employer through the implementation of the Improving Working Lives standard, promoting careers in the NHS and facilitating return to practice.   |
| XL      | Age Profile of Medical Devices in Europe. The Coordinating Committee of the Radiological and Electromedical Industry (2003). Their "golden rule" is that less than 40 per cent of the equipment base should be more than 5 years old.   |
| XLİ     | Guidance on commissioning NHS hospital-based care involving anaesthesia, pathology and radiology services.<br>Intercollegiate Service Specialties' Committee (2004).  |
| x∟ii    | NHS Cancer Care in England and Wales. Audit Commission/CHI (2002).  |
| XLIII   | The National Peer Review Exercise appraised performance of hospitals against the Manual of Cancer Service Standards (2000) which built on the Improving Outcomes Guidance. The exercise is to be repeated in 2004.  |
| xliv    | For example: British Association of Surgical Oncology: guidelines for surgeons in the management of symptomatic breast disease in the United Kingdom. 1998; NICE: Improving outcomes in urological cancer. 2002; Smith et al. Evidence of the effect of specialisation on the management, surgical outcome and survival from colorectal cancer in Wessex. British Journal of Surgery 2003; 90(5): 583-592.  |
| XLV     | Hillner et al. Hospital and physician volume or specialization and outcomes in cancer treatment: importance in quality of cancer care. Journal of Clinical Oncology 2000;18: 2327-40. Based on 100,000 procedures.  |
| XLVİ    | The good practice guidelines were devised by the Joint Council of Clinical Oncologists in 1993.   |
| XLVII   | The four tier structure is explained at xxxviii.  |
| XLVIII  | These include improving pay and conditions, increasing the number of students entering training, encouraging the NHS to become a more flexible and diverse employer through the implementation of the Improving Working Lives standard, promoting careers in the NHS and facilitating return to practice.   |
| xlix    | Royal College of Radiologists. Equipment, Workload and Staffing for Radiotherapy in the UK 1997-2002 (2003).  |
| L       | As shown, for example, by: McCulloch et al. Mortality and morbidity in gastro-oesophageal cancer surgery: initial results of ASCOT multicentre prospective cohort study. BMJ 2003; 327: 1192-1197. Tammemagi et al. Impact of comorbidity on lung cancer survival. International Journal of Cancer. 2003; 103(6): 792-802.  |
| Lİ      | See, for example, Schrijvers et al. Socioeconomic status and comorbidity among newly diagnosed cancer patients. Cancer. 1997; 80(8): 1482-8.  |
| Lİİ     | Taylor and Cheng. Social Deprivation and Breast Cancer. Journal of Public Health Medicine 2003; 25: 228-233.  |
| LIII    | Jack et al. Geographical inequalities in lung cancer management and survival in South East England: evidence of variation in access to oncology services? British Journal of Cancer 2003; 88: 1025-1031.  |
| LİV     | Cancer treatment policies and their effect on survival: lung. Northern & Yorkshire Cancer Registry and Information Service (1999).  |
| LV      | Peake et al. Ageism in the Management of Lung Cancer. Age & Ageing 2003; 32:171-177.  |