

Tackling cancer in England: saving more lives



REPORT BY THE COMPTROLLER AND AUDITOR GENERAL
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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 it is clear that they will save lives;
 - To detect cancer earlier and heighten public awareness of symptoms;
 - To identify people with suspected cancer in general practice and have them assessed promptly by specialists;
 - To speed up diagnosis; and
 - To ensure the most appropriate treatment is available to all.
- 5 The Department of Health has set out a programme to build capacity through additional facilities and an expanded workforce in order to meet these challenges. This study considers actions being taken in relation to the areas above by drawing on a wide range of published and unpublished data for this country and overseas, advice from experts, and surveys of Networks, GPs and cancer consultants. 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 survival¹:

- Incidence** The number of cancers which occur each year in a population of given size¹.
- 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;

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



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

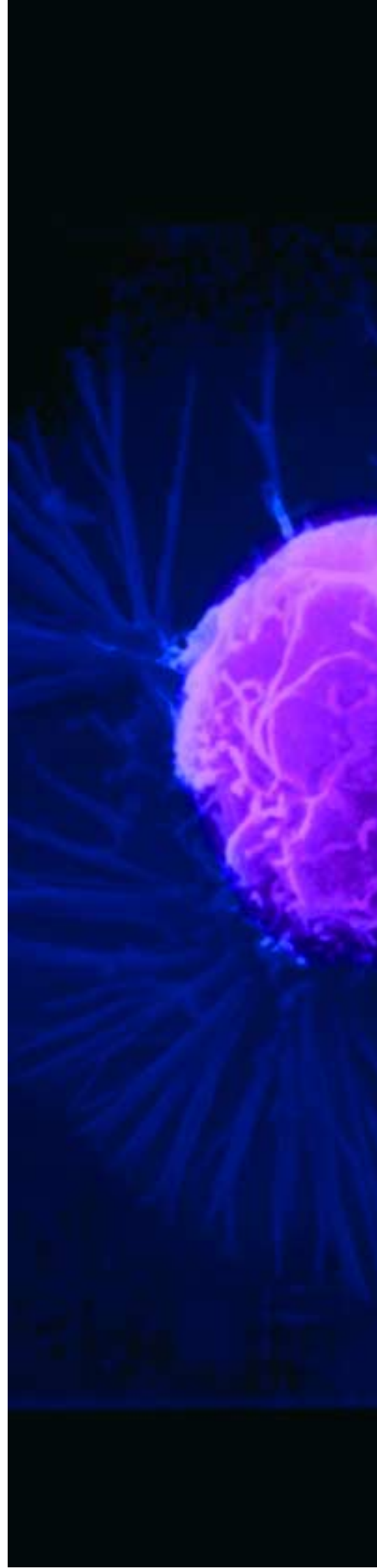
Good practice is being introduced to build further on improvements in outcomes in the 1990s, but progress varies by cancer and locality

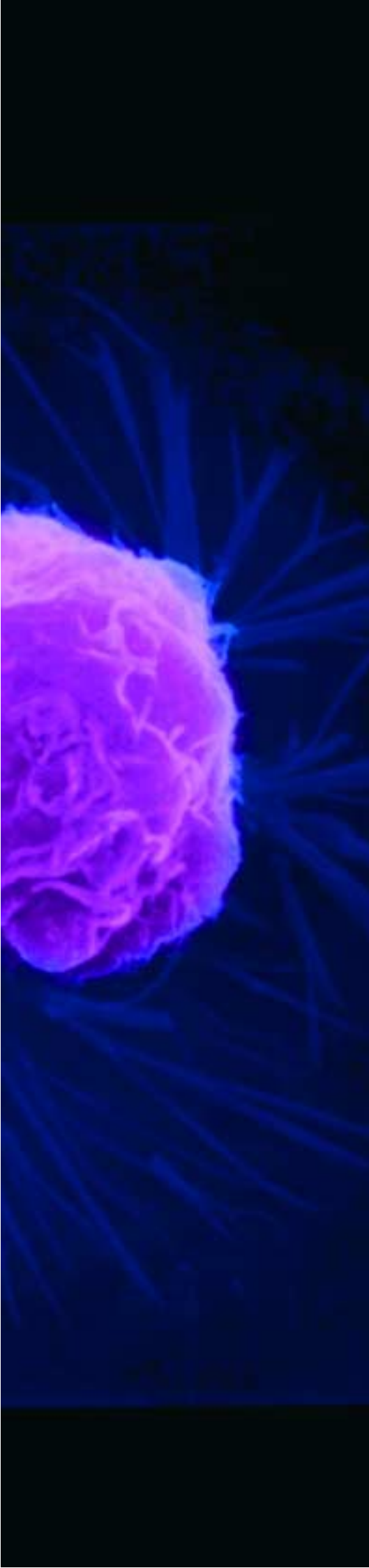
- 16 The NHS has concentrated on cancer prevention measures for behaviours which clearly increase the risk of cancer, such as tobacco consumption, but these measures will take time to have an impact. The NHS set up a national network of services in 2000 to help smokers give up. It is one part of the wider tobacco control strategy in the White Paper "Smoking Kills"ⁱⁱ. 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.



Smoking kills

- 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.



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

Recommendations

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

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