

Cancer care in the NHS

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The authors have written in a personal capacity and their views do not represent those of their institutions.

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Executive Summary

- Over the last five years the NHS has invested nearly £2.0 billion in improving cancer services using a traditional public sector model. The National Cancer Plan published in 2000 led to a massive injection of funding. We do not believe cancer patients have obtained the best value possible from this remarkable investment.
- Changes in the control of funding flow in the NHS have led several NHS agencies – Primary Care Trusts, Strategic Health Authorities, provider trusts, Cancer Networks and the Department of Health – getting involved in decisions on cancer. Some have little relevant expertise and many are overwhelmed. Cancer patients often live in poor health unnecessarily for long periods of time due to a lack of co-ordination of their care by overstretched treatment services.
- Several hundred new, highly paid administrative staff have been appointed to re-engineer the journey of patients but this has not resulted in an increase in clinical capacity because of predictable professional staffing shortages on the front line.
- The patient voice in determining the future of cancer services has so far been a whisper emanating from a few, well meaning but unrepresentative, professional patients who do not rock the boat. There is no effective choice available for cancer patients.
- Delays in first referral have been reduced for those with possible cancer symptoms but the queue for access to diagnostic services for those whose symptoms do not follow a clear pattern and yet still are found to have cancer has lengthened. A Royal College of Radiologists report demonstrated appalling delays in access to curative radiotherapy with 72 per cent of patients in 2003 being treated outside the maximum acceptable delay period compared with 32 per cent in 1998. Many new machines are lying in boxes because of staff shortages.
- The Department of Health's target for 2005 – a wait of one month from diagnosis to first treatment – is in our view impossible to achieve. Such a wait would be unacceptably long in most European countries and certainly in North America.
- Despite the use of lottery money to improve diagnostic services, there are still huge delays in obtaining scans and pathology before a decision can be made on the best treatment to offer an individual. There is no co-ordinated national IT system in place to maximise the use of facilities across artificial administrative boundaries.
- Although £124 million in extra funding has been allocated each year for cancer drugs, there is still strong evidence of postcode prescribing with less than 5 per cent of women with breast cancer receiving Herceptin in

Derbyshire compared with 90 per cent in Dorset. The drug budget is set to soar with the European registration of several new high cost, targeted molecular therapies now available in the USA. The cancer postcode lottery is set to continue unabated.

- In terms of Britain's social and economic challenges we believe the Cancer Plan is delivering poor value for money. It is operating in a top down, confused bureaucracy. Although outsourcing diagnostic services to the private sector is beginning to increase both capacity and efficiency, there are few innovative partnerships in the delivery of cancer care. True reform is now essential.
- We are writing this with a great sense of urgency. The Cancer Plan is simply not delivering as hoped and there are no reasons for expecting any dramatic improvements in the future. In the interests of patients we must look at ways of bringing about a rapid improvement in the situation.
- There are feasible, fundable ways forward available. Essentially cancer services should benefit from the economic incentives that have improved the situation in other areas of care including elective surgery and cardiac surgery. While other areas of care are benefiting from greater pluralism, cancer services are still in the era of a complete NHS monopoly within which cancer networks are promoting cartels to block out competition.
- In particular, within two years, 30 per cent of diagnostics, radiotherapy and chemotherapy should be outsourced to the independent sector. This would drive innovation, investment and increase the quality of services provided. Such pluralism of provision would be the basis of real patient choice.
- In the future the prevalence of cancer will rise trebling the number of people living with cancer in Britain to three million at any one time. This will put further pressure on process and outcomes. Real improvement will not be achieved by simply giving more money to a burgeoning bureaucracy. It requires a serious commitment to reform.

1. Background

Cancer affects one in three of us. There are over a million people in Britain today living with cancer. This could rise to three million within 20 years. It is a complex disease crossing traditional speciality boundaries in medicine. It requires skilled diagnostic as well as treatment facilities and the effective interaction of several professional groups. Cancer care therefore is therefore an excellent surrogate for the health of the NHS.

The past problems with Britain's cancer services

The NHS Cancer Plan¹ was born out of major deficiencies in care going back three decades. The Calman-Hine group came up with a structural plan in 1994 but no funding was forthcoming to implement change. Doing something for cancer became a major political imperative after the Eurocare-2 study showed that the United Kingdom was low in the league table of five-year survival for several common cancers.² From a system with glaring equipment deficits, staff shortages, and gross inequity in use of high cost drugs, the Cancer Plan created an infrastructure for change based on a classic public sector model. The Plan has only partially fulfilled its ambitions because of problems of local inertia, divergence of priorities, and the inability to resolve severe professional staff shortages. Cancer fatigue is now engulfing many of the administrative functions within the NHS.

The NHS Cancer Plan

The NHS Cancer Plan identified the need for fast, convenient, high quality care with patients at the centre. It set out the actions and milestones to deliver the fastest improvement anywhere in Europe within five years based on a massive injection of funding. It included three major commitments:

- To reduce the delay from referral to the beginning of treatment to two months;
- To reduce smoking in lower socioeconomic groups; and
- To invest an extra £50 million in palliative care each year from 2004.

Several hundred new administrative staff have been appointed to re-engineer the journey of cancer patients. But this has not been followed by an increase in clinical capacity because of staffing shortages and the lack of a uniform information technology platform to ensure smooth patient flow and good quality control. A review of the 34 cancer networks has shown considerable variation in uptake of new money for cancer, with 10 networks spending less than 80 per cent and three less than 60 per cent of their allocated funding.³

¹ *The NHS Cancer Plan*, Department of Health, 2000.

² Berrino, F., Capocaccia, R., Estève, J., Gatta, G., Micheli, A., Hakulinen, T., et al, *Survival of cancer patients in Europe – The EURO CARE-2*, IARC, 1999.

³ Richards, M., *Investment in cancer in 2001-02 and 2002-03*, Department of Health, 2003.

2. The current situation

Two recent Department of Health documents have presented progress in glowing terms, highlighting greater funding, more staff and more equipment.⁴ Two other reports, however, have been much more critical.

A recent document from the House of Commons Committee of Public Accounts makes depressing reading. It details protracted and worsening delays, postcode prescribing and an increasing gap in the outcomes obtained by rich and poor patients despite increased resources.⁵

The All-Party Parliamentary Group on Cancer conducted a Parliamentary Inquiry in the summer of 2004.⁶ In a hard-hitting document the Group were critical of how cancer monies were simply disappearing into the black hole of the NHS with almost no accountability. Indeed it pointed out that twice within the last two years the Government has felt compelled to launch an internal investigation into what happened to the money. The system simply cannot cope with its own complexity. As the report stated:

- "PCTs may be unequal to the task of planning how best to spend the huge amounts of money being pumped into the NHS. This has worrying implications for the provision of all NHS services but particularly for national priority areas such as cancer."
- "Locally we have struggled with radiotherapy where we have 16 PCTs using a cancer centre and require the agreement of all 16 parties to do anything."
- "The All Party Group is not convinced that PCTs working individually are the best commissioners of cancer services."
- "The Minister stated that there was still time for PCTs to go on growing into their role but we remain unconvinced that PCTs are the most appropriate organisations for commissioning services."

The report clearly struggled with the bureaucracy of the NHS. Its recommendations, while reasonable, cannot overcome the serious problem of poor co-ordination from the complex and over bureaucratic structures in today's NHS.

Although we agree there has been a lot of activity, with nearly an extra £2.0 billion spent on UK cancer services in the past five years, we would question its value for money. As the following chapters explain:

⁴ *Maintaining the momentum*, Department of Health, 2003; *The NHS cancer plan and the new NHS – providing a patient-centred service*, Department of Health, 2004.

⁵ *Tackling cancer in England: saving more lives*, House of Commons Committee of Public Accounts, December 2004.

⁶ *Meeting national targets, setting local priorities: the future of cancer services in England*, All-Party Parliamentary Group on Cancer, 2004.

- The staff expansion has been only modest and with the reduction in working hours, the new consultant contract and the emphasis on multidisciplinary (MDT) meetings, has probably had little impact on direct patient care;
- 75 per cent of the new radiotherapy machines are simply replacements of existing machines, often long overdue; and
- A national cancer IT system is still completely absent.

We sympathise with the National Cancer Director in his difficult task of acting as a government spokesman without having the power to implement effective change.

3. Diagnosis

Much acclaim has been given to the achievement of the two-week target from urgent referral by a general practitioner to consultation with a specialist but there is little evidence to show this was a serious issue before 2000, despite public statements to the contrary by ministers.⁷ Nevertheless, patients have welcomed improvements in coordination. One-stop clinics for breast and other cancers reduce the anxiety associated with not knowing the detailed treatment plan for several weeks. Such initiatives depend on local enthusiasm as much as central directives, and most were under way before the cancer plan was implemented.⁸

Perhaps the biggest disappointment has been the inability to reduce the delay from referral or diagnosis to first treatment. Patients with breast cancer are more likely to be treated within the target time than those with other cancers because the definitive treatment is usually the initial surgery rather than radiotherapy or chemotherapy. Surgeons were already adopting a more streamlined approach to managing cancer patients stimulated by the success of their voluntary national audit system.⁹

Waiting time target data published on the Department of Health website shows no improvement for any of the main cancers throughout 2002 or 2003 and increased delays for urological and in some centres for gynaecological cancers.¹⁰ Previously displayed graphs have now disappeared with only data showing improvements being posted. The target itself for 2005, which in our view is impossible to achieve – a wait of one month from diagnosis to first treatment – would still be unacceptably long in most European countries and certainly in North America.

Fast tracking diagnostic imaging is overloading the system and leading to delay for many. Although private sector initiatives have had some impact the sheer scale of the problem has been underestimated for a decade. The arrival of new technology such as PET-CT currently used for most cancer patients in the USA as a staging technique prior to radical therapy is likely to overwhelm an already overloaded system.¹¹ The Royal College of Pathologists estimates that over a third of histopathology posts (400) will be vacant by 2005.¹² The future of cancer therapy will crucially depend on skilled tissue analysis to ensure individually tailored treatments. New high cost drugs will need a far

⁷ Hutton, J., *Today*, BBC Radio 4, 26 May 2003.

⁸ Sikora, K. and Bosanquet, N., Cancer care in the UK: new solutions are needed, *British Medical Journal*, 2003; 327: 1044-6.

⁹ Robinson, D., Bell, C., Moller, H. and Basnett, I., Effect of the UK government's 2-week target on waiting times for women with breast cancer in southeast England, *British Journal of Cancer*, 2003; 89: 492-6.

¹⁰ Cancer Services Collaborative - national monthly progress reports (www.modern.nhs.uk/cancer).

¹¹ *Imaging for oncologists*, Royal College of Radiologists, London, 2004.

¹² *Submission to NICE on liquid based cytology for cervical screening*, Royal College of Pathologists, 2002.

more sophisticated diagnostic and monitoring service than is currently possible in the NHS.

4. Surgery & radiotherapy

Surgery remains the single most effective treatment for cancer. It is increasingly conservative, able to retain organs and structures. New technology permits minimally invasive surgery for many types of cancer. This allows increased day case work, less use of intensive care, and fewer beds, and should reduce costs. The separation of diagnostic from emergency surgery through the creation of NHS-run and privately-run Treatment Centres, funded by the NHS, should also reduce delays in cancer surgery.

Radiotherapy

Modern linear accelerators allow radiation doses to be delivered to the precise shape of the tumour, killing the cancer cells and avoiding normal surrounding tissue. The machines allow higher doses to be used with fewer side effects. Although 56 linear accelerators have been purchased with lottery funding, most have been replacement machines and many are still lying in boxes in warehouses. The effect of the new machines on waiting times has been reduced by shortages of radiographers, leading to temporary closures of existing machines. Equipment costs have doubled over the past 10 years and precision therapy has greatly increased staffing requirements. A recent Royal College of Radiologists report has clearly demonstrated appalling delays in access to curative radiotherapy.¹³ 72 per cent of patients in 2003 were treated outside the maximum acceptable delay compared with 32 per cent in 1998. Table 1 shows the percentage of radiotherapy centres with waiting times shorter, longer or the same between 2003 and 1998 audits.

Table 1: Percentage of radiotherapy centres with waiting times shorter, longer or the same between 2003 and 1998 audits			
Treatment intent	longer	same	shorter
Radical	73	15	12
Palliative	44	39	17
Adjuvant	73	11	16

Source: Ash, D., Barrett, A., Hinks, A. and Squire, C., Re-audit of radiotherapy waiting times 2003, Clinical Oncology 2004; 16: 387-394.

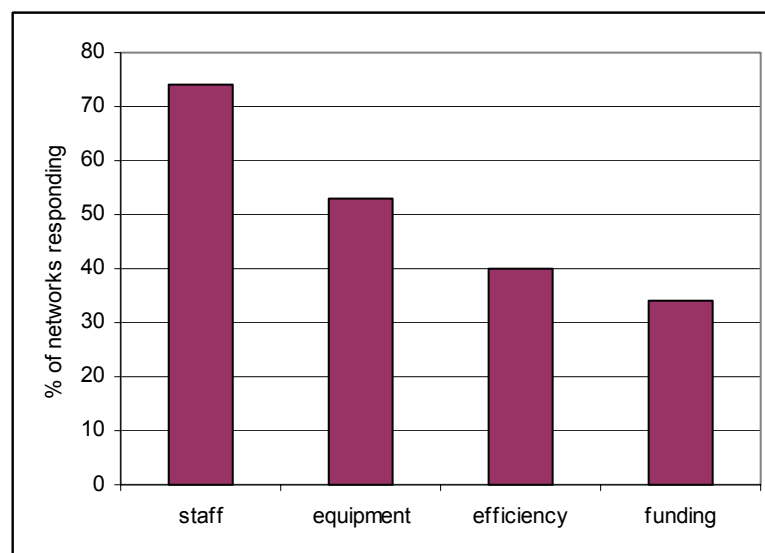
Failure to meet the target is mainly due to shortages of equipment and staff, which no amount of re-engineering can overcome. The UK has less capacity

¹³ Ash, D., Barrett, A., Hinks, A. and Squire, C., Re-audit of radiotherapy waiting times 2003, *Clinical Oncology* 2004; 16: 387-394.

for treatment than other European centres with 3-4 linear accelerators per million population compared with France (6.1), Holland (4.7), Germany (4.6) and Italy (4.3). Patients often have to wait three months, and some up to six months, because of a shortage of radiographers. A study from Glasgow found that 21 per cent of lung cancer patients became unsuitable for curative treatment during the wait for radiotherapy.¹⁴ The problem is made worse by the increased staff time needed for new precise radiotherapy techniques. Despite the shortage, universities are not greatly increasing the places on radiography courses and the loss from such degree programmes still exceeds 30 per cent.

Staffing is also a problem in other specialties. Although the number of oncology specialist registrars being trained has risen, it has been offset by earlier retirement of consultants. In addition, consultants face many new demands on their time – attending multidisciplinary team meetings, appraisal, and accreditation – as well as longer consultations as patients become better informed. In some specialties critical for good cancer care, staff shortages are actually increasing.¹⁵ Interestingly in the National Audit Office survey of Cancer Networks' views, staff shortages were the main perceived problem constraining radiotherapy delivery.

Figure 1: Cancer Networks' views on radiotherapy constraints



Source: National Audit Office, 2004

¹⁴ O'Rourke, N. and Edwards, R., *Lung cancer waiting times and tumour growth*, *Clinical Oncology*, 2000; 12: 141-4.

¹⁵ *Equipment, workload and staffing for radiotherapy in the UK 1997-2002*, Royal College of Radiologists, London 2003.

A number of factors will increase the future demand for radiotherapy. These include:

- An overall increase in the number of cancer patients;
- An increasing proportion of cancer patients receiving radiotherapy;
- Achieving a more equitable access to radiotherapy services; and
- New medical technology to enhance precise dose delivery

Cancer drugs

The elimination of postcode prescribing for cancer drugs is a clear political imperative. Although reviews by the National Institute for Clinical Excellence (NICE) have been assiduously carried out and an extra £124 million spent on drugs, there are still reports of diversity in policies in NHS centres and purchasers.¹⁶ The nationally agreed diagnostic process to assess women with breast cancer for over expression of c-erbB2 before treatment with trastuzumab for breast cancer is simply unavailable in some areas, creating a novel form of rationing. A report from CancerBACUP has shown that prescribing rates per head of population for 16 drugs appraised by NICE varied almost four fold.¹⁷ This cannot be explained by case mix differences alone. Astonishingly there is no central recording system of drug use and data can only be taken from drug company consultancy services that monitor supply by wholesalers to the NHS.¹⁸ Table 2 shows the wide variation in the percentage of eligible women receiving Herceptin for breast cancer over a year after NICE guidance was issued.¹⁹

¹⁶ Another NICE mess, *Lancet Oncology*, 2002; 3: 38-40.

¹⁷ Health Secretary demands patients have equal access to cancer drugs, *British Medical Journal*, 2003; 327: 1007.

¹⁸ *Variations in the usage of cancer drugs approved by NICE - report of the review undertaken by the National Cancer Director*, www.doh.gov.uk.

¹⁹ *Tackling cancer in England: saving more lives*, National Audit Office, 2004.

Table 2: Variations in percentage of eligible breast cancer patients receiving Herceptin one year after NICE guidance

Cancer network	% eligible women on drug
Dorset	90
SE London	55
Norfolk	52
Sussex	48
Kent	24
Leicester	25
North Trent	22
Essex	18
Birmingham	14
Derby	5

Source: Ash D., Barrett A., Hinks A. and Squire C., Re-audit of radiotherapy waiting times 2003, Clinical Oncology 2004; 16: 387-394.

Treatments for cancer are advancing rapidly, and the Plan has to aim at a moving target to satisfy an increasingly informed and medically sophisticated public. Patients may want to be treated at centres that can provide innovative therapies if they are not universally available. Over the past five years, pharmaceutical research has shifted away from the search for new cytotoxics to drugs acting on defined molecular mechanisms. Nearly 600 molecules are currently undergoing clinical study and the next five years will see powerful new technology unleashed in the clinic (Figure 2). The cost of drugs is set to soar (Figure 3).

Figure 2: Predicted launch dates for molecular therapies in the USA

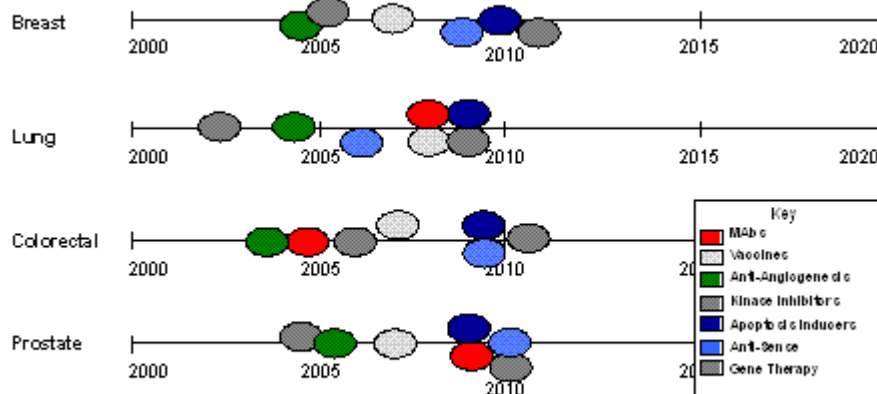
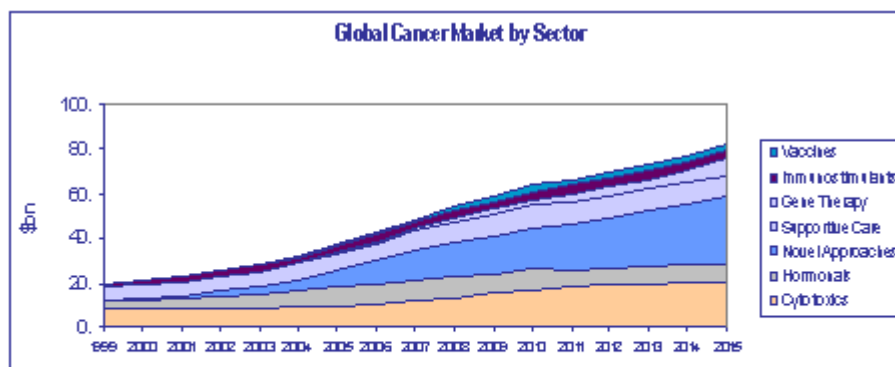


Figure 3: Cancer market set to triple by 2010



- 2010 sales \$64bn, CAGR 12% driven by
 - new technology - targeted therapies
 - earlier intervention
 - patient numbers (ageing population - other diseases controlled)

Source: McKinsey Consulting, New York

The United Kingdom uses chemotherapy less than other European countries for all types of cancer. The National Institute for Clinical Excellence has recommended more aggressive treatment of some cancers, and this will increase financial pressures. Table 3 lists examples of high cost drugs now available for some common cancers in the USA.

Table 3: Marketed targeted therapies			
Drug	Generic	Manufacturer	Yearly cost
Herceptin	trastuzumab	Roche	£60,000
Mabthera	rituximab	Roche	£40,000
Glivec	Imatinib	Novartis	£50,000
Erbitux	cetuximab	BMS	£60,000
Avastin*	bevacizumab	Genentech	£70,000
Tarceva*	erlotinib	Roche	£65,000
Iressa*	gefitinib	AZ	£40,000
* not yet available in UK			

Information technology

Much of the chemotherapy prescribing carried out in cancer centres is paper-based and prone to error. It is no longer safe to prescribe modern chemotherapy without the assistance of IT to ensure that the dosing is correct and that dangerous interactions do not occur. It is inevitable that paper-based systems lead to incorrect prescribing which in the case of chemotherapy will often be harmful and sometimes even fatal. If such a dangerous system existed for other procedures such as surgery it would be regarded as completely unacceptable. The same paper-based systems are virtually impossible to audit so the ongoing errors are just not detected.

The National IT Programme does not have any detailed plans for electronic prescribing in oncology. It assumes that this will somehow develop as part of the overall Programme but the companies involved in developing it have virtually no experience of electronic prescribing for oncology. Several sophisticated oncology electronic prescribing systems are available but there is no national system to make sure these are implemented and individual trusts do not have the funds to do this on their own. If left to develop as part of the National Programme this same situation will still exist in many years time.

Electronic chemotherapy prescribing systems should be urgently implemented in all oncology units. This will improve quality of care and reduce errors, provide sophisticated audit and insure the appropriate treatment is given.

5. Staffing

The national shortage of crucial staff, particularly radiographers, has contributed significantly to the disappointing progress that has been made with implementation of the Cancer Plan. Much could be done, however, if some creative thinking was used to maximise the use of the people available. Many radiology and radiotherapy units close at 5pm and argue that the reason for this is the lack of staff. The same staff, however, would often be pleased to work overtime and allow the scanning and radiotherapy facilities to continue to operate late into the night and on weekends, provided they were paid adequately. This would immediately improve the availability of scanning and radiotherapy without having to wait several years for the appropriate staff to be trained. The cost would be relatively small as the equipment and other facilities have already been purchased.

Multidisciplinary teams

Multidisciplinary team (MDT) meetings have been an important component of improving patient care but have now become over-bureaucratised. MDTs have been established at enormous cost in terms of medical and nursing manpower which could otherwise be devoted to patient care. These meetings take up many hours in the week of each for every consultant as well as that of many specialist cancer nurses and radiographers. As with any system set up by national edict it is highly inefficient and very wasteful of human resources. All patients have to be discussed in detail, however obvious or straightforward their treatment. An urgent look at streamlining these meetings so that they can focus on those patients whose care is difficult and skim over those whose care is straightforward would immediately release many hours of consultant, registrar and nursing time which could be more profitably spent with patients. The effective use of IT could lead to a far more streamlined programme with MDTs being carried out on-line.

6. The way forward

Patients with cancer should have the same principles of choice and variety of providers that are being offered in other areas of health care. Inclusion of cancer care in national tariffs open to competitive tendering will allow the relative costs of different providers to be dissected. We could start by pilot programmes in diagnostic services and radiotherapy, with patients being offered alternative services if they experience delays. Unless opportunities for innovation are increased with appropriate incentives, health investment will be tilted into other areas and cancer care will become disadvantaged yet again.

Big improvements in access and capacity over the next two years are essential to take the momentum forward. Local private sector initiatives, in diagnosis, surgery and radiotherapy, could raise productivity appreciably in cancer centres. Open tendering would encourage a range of providers and end the block on investment and innovation. We need to improve the information available to patients on quality and access.

We are simply advocating that cancer patients should be able to benefit from the same key principles of patient empowerment, choice and competition which have been strongly advocated for the NHS by the Secretary of State. We cannot stand by and watch while such a vital area of service falls behind the rest of the NHS.

We are optimistic about the opportunities for improving use of scarce resources across cancer prevention and care. There is much that is positive about the aim of a patient-centred service with more focus on long term illness. There is much to admire about the dedication and commitment of staff in the NHS.²⁰ In terms of Britain's long term social and economic challenges, however, we believe the NHS Cancer Plan has delivered poor value for money. It is essential to search for new initiatives which will improve the situation.

For the longer term cancer services would have much to gain from a greater variety of providers. This would draw in international capital and expertise. Reliable and effective services are becoming more feasible and fundable in smaller, networked, user-friendly cancer "hotels" as well as in larger teaching centres. The professional and human commitment of staff in cancer care could be used more effectively to improve process and outcomes for many.

Mortality from cancer now counts for 30 per cent of all deaths in those under 70 and 40 per cent for women. These proportions are likely to increase further as mortality from coronary heart disease reduces. Cancer patients often live in poor health unnecessarily for long periods of time due to a lack of co-ordination of their care by overstretched treatment services. The Cancer

²⁰ Bosanquet N., *The NHS in 2010, Reform*, 2004.

Networks act as cartels dividing up the workload. We need to take steps to ensure that cancer patients benefit from a greater variety of providers:

- There are new challenges in building partnerships with patients with higher levels of concern about lack of information. Cancer services have often scored unusually low in survey evidence on the quality of communication with patients. Patient Care Advisers are needed to explain the merits of different providers.
- Within two years, 30 per cent of diagnostics, radiotherapy and chemotherapy should be outsourced to the independent sector. This would drive innovation, investment and increase the quality of services provided. Such pluralism of provision would be the basis of real patient choice.
- Patients need to be involved in funding considerations with the introduction of incentives for patients not to use high cost interventions of low benefit. We need to let patients drive the agenda involving cancer experts more widely in planning for a complete financial, operational and strategic overhaul of cancer services.
- The aim should be to create an innovative culture of reform embracing private sector expertise and investment.

In the future the prevalence of cancer will rise trebling the number of people living with cancer in Britain to 3 million at any one time. This will put further pressure on process and outcomes. Even if there are increases in real funding, such numbers point to a situation in which real expenditure per patient will rise little. Sustained improvement in system performance is essential. Real improvement will not be achieved by simply giving more money to a burgeoning bureaucracy. It requires a serious commitment to reform.

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