



NATIONAL SERVICE FRAMEWORK ASSESSMENTS NO.1
NHS Cancer Care in England and Wales

DECEMBER 2001

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Foreword

Despite advances in treatment and survival underpinned by decades of research, cancer is still a frightening disease. All of us know of someone, whether friend or family, who has suffered cancer and hardly a day goes by without some news about cancer in the press, TV or radio. Cancer is a focus of concern for the Government and the National Assembly for Wales who have responded by developing and funding plans which will improve equity of access to high quality care and drive up treatment and survival figures.

However, it is important to review where cancer services stand at the moment, and how far they have travelled from publication of the Calman-Hine report in 1995. In their first joint report, CHI and the Audit Commission have collaborated to provide a useful and timely overview of the cancer patient's journey, from point of diagnosis, through treatment and follow up, attempting at each stage of the pathway to view the service from the patients point of view. Tribute must be paid to the energies, skill and commitment of all those involved in this project and in their condensation of results into a clear and readable format. Particular thanks should go to the many patients and health professionals who contributed their views and experiences to the report.

What does it tell us? There have been undoubted improvements in service delivery, but there is still a sense that progress has been patchy and that much has yet to be achieved. This report will help to inform those responsible for planning and providing cancer services, at all levels, in their strenuous efforts to maintain the upward trend in cancer care in the UK.

David Kerr

Professor David Kerr

Rhodes Professor of Therapeutic Sciences and Clinical Pharmacology, Chair of CHI National Service Framework Programme Board and CHI Commissioner to 31 July 2001.



Acknowledgements

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Executive summary

Introduction

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This review of cancer services, undertaken by the Commission for Health Improvement (CHI) and the Audit Commission (AC), is aimed at the general public as well as those with a specialist interest in this subject. Hallmarks of a good service, together with questions that patients might ask, are set out at the end of relevant chapters. The review is based on extensive research; further detailed information is available in supporting papers and data, published separately and available on the CHI and AC web sites.

The review addresses progress in implementing recommendations from a key report on cancer services in England and Wales, published in 1995 (the Calman-Hine Report). This report recommended major organisational changes at local level, involving the introduction of cancer centres and units working together within cancer networks. It also recommended changes in professional practice, such as increased specialisation in cancer and more team working among those providing treatment and care. It also set out principles for services, suggesting that they should be accessible, provide good information and choice, and ensure support for patients throughout their experience of cancer.

Since 1997, the policy context for cancer services has changed. Cancer is viewed as a top priority and new resources have been committed to its treatment and care. In England, there is a Cancer Action Team and a National Cancer Director; a National Cancer Plan, proposing national standards, has been published. The Cancer Services Collaborative has been set up to develop good local practice and now covers all of England. Guidance on clinical standards has been issued on a regular basis.

In Wales, an expert advisory committee was set up following the Calman-Hine Report, which published its own report in 1997 establishing the way forward (the Cameron Report). In addition, a national health plan has emphasised a commitment

to further developing and improving cancer services, including minimum standards for the care of common cancers. Targets for maximum waiting times between an urgent GP referral and a hospital clinic appointment have been set in both England and Wales.

The Cancer Plan for England, providing a policy framework for cancer services for the next five years, was published in autumn 2000. Because the detail of the plan was not fully known at the time the fieldwork began, we do not comment on the plan as such. The information collected by our review will provide a baseline against which progress in meeting the requirements of the plan can be measured.

The Calman-Hine Report provided an important impetus in setting an agenda for the development of cancer services, but it contained no central plan for implementing its proposals and provided no resources for this task. Because of the devolved nature of NHS management across the UK, each English region and Wales necessarily developed its own strategy and approach. This has resulted in great variation in the way that cancer services are delivered and organised, as demonstrated throughout this review. Despite the different approaches in England and Wales, the same issues regarding cancer services arise in both locations.

Both CHI and the AC are committed to improving patient centred care. Although typically defined as addressing patients' individual needs, this term can usefully be expanded to cover the importance of the whole system being oriented around patients' needs. Under this wider meaning, cancer services are not yet properly patient centred, with professionals working well together and alert to each others' roles.

Obtaining a diagnosis and planning treatment

Key findings from the research are:

- Most patients in our research felt the diagnosis of cancer had been given sensitively, but some had poor experiences; they welcomed the involvement of a specialist nurse at the time of diagnosis, but these are in short supply for many types of cancer.
- Nearly all hospitals are meeting the requirement that patients with suspected urgent cancer be seen by a specialist within two weeks of referral.
- Many patients experience serious delays in obtaining some tests; this is partly due to shortages of imaging equipment (CT and MRI scans) and this is now being addressed. Many machines are also not used as fully as possible and some areas are unable to recruit staff, such as radiographers and pathologists.
- GPs' ability to discuss the diagnosis and prognosis with patients is often hampered by lack of information from consultants.

Treatment and care

Key findings from the research are:

- Many patients obtain urgent surgery relatively quickly, but some are having to wait for a month or more.
- Waiting times for radiotherapy, even for urgent treatment, are a problem in some areas, varying with the type of cancer and urgency of need.
- Despite growing specialisation in cancer (and sub-specialisation) among surgeons, many patients are being operated on by non specialists. Most medical and clinical oncologists see patients with more than one type of cancer and some are total generalists.
- About half of all patients with cancer receive some chemotherapy, varying with the type of cancer and the practice of individual consultants. This may be prescribed by medical or clinical oncologists, but many hospitals do not have a medical oncologist.
- Radiotherapy machines are very unevenly distributed and many are old; there are plans to replace old equipment and to iron out inequalities. There is also great variation in the efficiency of machine use, arising from differences in prescribing, the hours during which machines are used and the availability of staff.
- Multidisciplinary teams, which comprise lead surgeons or physicians with other doctors and specialist nurses, are increasingly the norm. However, there is still considerable progress to be made in arrangements for some types of common cancer. Some teams do not meet frequently and do not involve all relevant staff. Communication with others outside the team, such as GPs or district nurses, can prove a problem.
- Many trusts do not have agreed policies for the management of many cancers and, where policies do exist, it is unclear whether they are followed because practice is not audited.
- Hospital discharge is not always undertaken with proper planning, so that GPs and district nurses can be unaware that a patient has gone home, sometimes without necessary services or equipment being arranged. It can be unclear whether the GP or consultant is responsible for patient follow-up after treatment.
- Patients found their consultants, nurses and others to be very supportive throughout their treatment. GPs could sometimes lose track of patients during the treatment period, due to lack of information from consultants.
- The services of psychologists or counsellors for patients with cancer are in limited supply. Many patients found cancer support groups to be helpful.

Palliative and terminal care

Key findings from the research are:

- Palliative care, involving the alleviation of symptoms and provision of emotional support, is needed by many - but not all - patients following or during treatment; many patients are reluctant to discuss palliative care, because of its implication that they are very ill: the term should not be confused with terminal care.
- There is considerable variation in the availability of specialist palliative care consultants and nurses and in the attention given by GPs and district nurses to patients needing palliative care. It is often unclear who has principal responsibility for providing such care.
- Availability of services outside of working hours is a particular problem. There are concerns that some patients are admitted to hospital purely as a result of this.
- Despite a striking growth of hospices over the past two decades, provision remains uneven across the UK. Patients tend to view hospices as a place to go when they are about to die, but many hospices also provide day centres in addition to inpatient beds and outreach services to patients' homes.
- It is well documented that most people with cancer would prefer to die at home, but only one quarter currently do so. GPs and district nurses tend to take on a more active role when patients are terminally ill, visiting them and their families.
- Some GPs and district nurses provide bereavement care to distressed relatives and specialist palliative care teams may also help here.

The organisation of cancer services

Key conclusions from the research are:

- Cancer networks, intended to achieve more co-ordinated planning and common treatment standards in an area, have now been established across England and Wales. There is evidence of close cooperation between clinicians in some networks, but service managers tend to operate more traditionally. The role of networks in commissioning services needs to be clarified.
- Leadership will be required on a range of planning and monitoring issues at network level. The workforce must be planned and managed across the whole network and the same is true of equipment requirements. Patients need to be consulted at network level in planning cancer services and in monitoring those currently provided.
- The process of designating cancer centres and units has not been easy, and the criteria used vary across the English regions and Wales. Day to day working arrangements, including communication, appointment systems and shared protocols, have not generally been fully worked out. Information systems are poor, so that those responsible for services cannot account for them to local clinicians or patients.

- Within individual centres and units, lead cancer clinicians have been appointed, as well as some lead cancer nurses and lead managers for cancer services, but the clinical leads still lack authority over other clinicians. Clinical governance should address this.
- The development of a common investment, workforce and planning strategy within networks will be difficult, as there will inevitably be winners and losers in the course of service improvement within network areas. Management may need to take some unpopular decisions, affecting professional jobs and conflicting with public views about the location of services.
- The new organisational change within the NHS, involving the abolition of health authorities and new strategic health authorities in England, will place heavy pressures on everyone and may serve to distract attention from improving cancer services.

Reflections on progress in cancer services

The Calman-Hine Report was important in developing good practice and bringing cancer to the forefront of the health agenda. Many improvements can be attributed to it, including the expansion of multidisciplinary working and plans to increase staffing and equipment. Other changes stem from policy developments since that time, including the reduction in initial waiting times.

Yet many key recommendations of the report are not yet fully implemented in all areas. From the patient point of view, there is poor communication and a failure to plan care in a systematic way between the different professionals involved. Many patients lack access to someone, such as a specialist nurse, who both knows about their cancer and can provide needed support. There are also failures in the wider system, so that patients do not always receive the best treatment or care. And there are striking variations in provision both across geographical areas and between patients with different types of cancer.

The inescapable conclusion is that formal policies and plans, however commendable, cannot ensure that services are provided in a truly patient centred way; a change in the attitudes and behaviour of those working with patients is also required. Priorities include a need to identify gaps in planning for individual patients, to give more attention to those cancers where services are not well developed and to resolve issues arising from the creation of networks at national and local level.

Many people across the NHS are working to improve cancer services; the criticisms throughout this review do not apply to all areas. But the goal must be for improvements and good practice found in some places to be replicated everywhere.



Introduction

The aims of the review

1

1.1 Most people know someone who is living with – or who has died from – cancer. Each person’s experience will be different. Some people have experienced the best treatment and care they could have wished for. Others may have had distressing experiences of delays, uncertainties and little help when it was most needed. There is no single cancer experience which applies to all people.

1.2 This review was undertaken by the Commission for Health Improvement (CHI) and the Audit Commission (AC) to document the experiences of people with cancer and the complexities of the multiple services with which they come into contact. We began the review following a request from the Government and the National Assembly for Wales (NAW) in 1999 that the two Commissions assess the implementation of recommendations of a major report on reorganising cancer services in England and Wales, published in 1995¹. This report reflected mounting public concern at that time about the nature and success of cancer services.

1.3 The focus of this review is the range of services received by people with cancer (or those who suspect that they might have cancer) from their initial point of contact with the National Health Service in England and Wales. It is concerned with the diagnosis, treatment and broad supportive care of cancer in adults. Health promotion, cancer prevention and screening are excluded on the grounds that they could not be covered properly in the time available. Our aim from the start was to take a hard look at what happens in practice and why. But we were also concerned to learn how the quality of services might be improved and resources used to best advantage. Indeed, improvements found in one area raise questions about why these cannot be implemented elsewhere.

1.4 The Cancer Plan for England, providing a policy framework for cancer services for the next five years, was published in 2000. Because we did not know the detail of the Plan at the time the fieldwork began, we do not comment on the Plan as such.

The information collected by our review will provide a baseline against which progress in meeting the requirements of the Plan can be measured.

1.5 Although this review includes messages for those concerned with policy and its implementation, it is intended to be more widely readable. Many different groups - as well as individual patients and families - may wish to learn more about cancer services and we hope that this review will prove accessible to them. Indeed, we have highlighted the most important issues for patients in a section called 'Hallmarks of a Good Service' and 'Some Questions Patients Might Ask' at the end of relevant chapters.

1.6 For those with a specialist interest, supporting papers providing more detailed information have been published separately. Supporting technical data, including graphs and tables, together with some commentary, are published in ten sections on the CHI and AC web sites and referenced here as supporting documents (SD1-10); this material is also available in paper form. Full details are set out in Annex 3.

1.7 This introductory chapter sets the context for the review. It starts by describing key changes in government policy and providing some brief background about cancer. It then discusses the meaning of patient-centred care and sets out the methods used.

The Calman-Hine Report, subsequent developments and current policy

1.8 This review considers progress in the implementation of the 1995 Cancer Report for England and Wales. This is known as the Calman-Hine Report after the two chairs of the Committee. Its main provisions need to be set out briefly.

1.9 First, the report made recommendations about the structure and organisation of local cancer services. There should be two types of facility delivering cancer services: units and centres. Cancer units would provide basic cancer services to their local population. Cancer centres should provide these basic local services, but should also provide a wider population with more specialist services, including complex surgery, radiotherapy and the more advanced forms of inpatient chemotherapy and sophisticated diagnostic techniques. These centres might comprise more than one hospital.

1.10 This plan was intended to make sure that patients could get treatment as close to their homes as possible, while developing some centres of specialisation and excellence. It also suggested a system of networks to bring together all cancer services in an area. Primary care was acknowledged to play an important role as a focus of care and arrangements for closer working with cancer centres and units were recommended.

1.11 Second, a number of recommendations focused on professional practice. There should be more surgical sub-specialisation in cancer and more specialist nurses, as well as greater multi disciplinary team working across all professions involved in cancer care. A lead clinician should co-ordinate the range of services provided within a cancer unit and make sure that they are of a high quality. Cancer units should include consultation in palliative medicine and access to counselling and other psychological support. The commissioning process, affecting the range of cancer services provided, should also be developed.

1.12 Finally, the Calman-Hine Report developed a set of principles for cancer services. These involve making sure that care is not only of good quality but also easily accessible, without the need for patients to travel long distances. There should be systems to make sure that cancer is recognised early. Patients should have good information, including about any options for treatment, and support throughout their experience, making cancer services much more patient centred. The principles are summarised in Box 1.1 below.

BOX 1.1 PRINCIPLES OF GOOD SERVICE (SUMMARY)

- High quality care, available to all, as close to home as possible
- Public and professional education to assist the early recognition of cancer symptoms, together with national screening programmes
- Clear information and assistance to patients and their families about options and outcomes
- Patient-centred services, taking account of patients' views and preferences
- Primary care involvement and good communication between different service providers at all stages
- Attention to psycho-social aspects of care at all stages
- Cancer registration and careful monitoring of treatment and outcomes

The Calman-Hine Report

1.13 The Calman-Hine Report served as an important first step in providing a vision for cancer services. But it did not establish any central plan for implementing its proposals. Because of the devolved nature of the NHS management structure, individual regions in England were expected to go about the process of implementation in their own way, in response to local need. As they would also be responsible for monitoring the new developments against recommendations, there was no central system for keeping an eye on progress in different areas. Moreover, no additional resources were provided at the time for these tasks.

1.14 Central support was provided in England for the development of national guidance on clinical standards, however. This has been published regularly involving rigorous reviews of the evidence and expert opinion. The first review in the series was called 'Improving Outcomes in Breast Cancer' (1996) and this was followed by similar guidance for colorectal (1997), lung (1998), gynaecological (1999) and upper gastrointestinal cancer (2001). Further publications are planned over the next four years, including updates of some earlier volumes. These publications came originally from a group known as the Clinical Outcomes Group (COG), so they are often referred to as the COG Guidance².

1.15 To carry out the recommendations of the Calman-Hine Report, each English region developed its own strategy and approach. Some pursued implementation more vigorously than others, designating centres and units and creating regional systems to set and monitor standards. Others, in contrast, encouraged development from below, expecting local health authorities and trusts to collaborate on the details of implementation. In Wales, a report was commissioned to address this issue³ and a co-ordinating group established to oversee and co-ordinate its implementation. Wales focused primarily on involving clinicians in developing and implementing minimum standards for cancer care as their first priority. The clear result of these varied approaches is that progress has been slow and patchy. This is shown throughout this review and is set out in a table in Annex 1.

BOX 1.2 THE NHS CANCER PLAN (2000)

"The NHS Cancer Plan set out the first comprehensive strategy to tackle cancer, spanning prevention, screening, diagnosis, treatment, care and research and development. It also established the investment needed to deliver these services in terms of staff, equipment, drugs, treatments and information systems.

It identifies four broad aims:

- To save more lives
- To ensure that 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, research and preparation for the genetics revolution, so that the NHS never falls behind in cancer care again."

Source: The Department of Health. The National Cancer Plan. London. DOH 2000

1.16 The new Government in 1997 brought in a shift in strategy and approach. It reaffirmed cancer as a top priority and set about introducing a number of changes. It created and supported central systems for implementing the Calman-Hine Report and monitoring progress and earmarked new resources for these tasks. Waiting times, not specifically mentioned in the report, were given a high priority. In England, in April 1999 a target was set of a maximum two week wait between an urgent GP referral and a hospital clinic appointment. This was originally only for patients with suspected breast cancer, but since then it has been extended to patients with any urgently suspected cancer⁴.

1.17 At the same time, organisational and other major changes were introduced. In England, a Cancer Action Team was established in 1999 and a National Cancer Director (often called the 'cancer czar') appointed to produce a plan for developing cancer services. The NHS Cancer Plan, proposing national standards for England was published in September 2000 alongside an investment programme⁵. Its broad aims are set out in Box 1.2. New national machinery was also put in place to support and monitor developments for cancer. This paid particular attention to the resources needed, including staff and equipment. In Wales, a programme office was set up in 1997, with dedicated funding. An NHS plan was published in 2001, including attention to cancer⁶. A commentary on its aims by the National Assembly for Wales is set out in Box 1.3.

1.18 Other developments to improve cancer services have followed. In England, referral guidelines for GPs were published in 2000⁷. A manual setting out standards and performance indicators for local networks was published in early 2001⁸. This was accompanied by a national system for peer review of the quality of services which is now under way. The National Institute for Clinical Excellence (NICE) has issued guidance about the appropriate use of some important cancer drugs, such as taxol, and will carry out further appraisals in the future. Cancer networks are no longer viewed as optional and pressure has been placed on local services to demonstrate improvements in access and quality. In Wales, minimum standards for the care of common cancers were issued in 1998 and 1999, and revised in 2000⁹. These covered a range of issues concerning cancer care, and included an initial maximum wait of ten working days for a consultation once a specialist deemed the situation to be urgent (except breast cancer, where it was five working days, later amended to ten). Fuller information on these policy developments is provided in Annex 2.

1.19 To set up and develop good local practice, the government in England launched the Cancer Services Collaborative in nine areas in 1999. These projects were intended to improve patients' experience by reducing delays and creating a more patient centred approach, with particular attention to certainty and choice. The collaboratives have reported a number of improvements in services in their areas, including reductions in waiting times.¹⁰ The programme has now been extended to the whole of England and is expected to deliver a substantial programme of change in all networks.

BOX 1.3 IMPROVING HEALTH IN WALES (2001)

"Through the Wales Cancer Service Co-ordinating Group (CSCG), progress has been achieved in identifying responsibilities in setting and monitoring standards for cancer services and in initiating new developments. There is now a need to build on this infrastructure and focus on objectives for the next five years. Rapid access for diagnosis and treatment are critical.

Further action is needed to ensure that, by December 2001, cancer patients, and their families and carers, in Wales can be assured that:

- They will have a consultant appointment within 10 days of receipt by the hospital of an urgent referral by their general practitioner
- They will receive a diagnosis and appointment for treatment as set in the published CSCG minimum standards for cancer care in Wales
- Their treatment and care will be discussed by the multidisciplinary team specialising in that disease
- They will have increasing access to specialist nurses with extended skills thus enabling more of their care to be carried out at home."

Source: National Assembly for Wales. Improving Health in Wales: A plan for the NHS and its partners. Cardiff. NAW 2001

1.20 Over the past four years, new resources have also been committed to cancer. To help reduce waiting times, £10 million per year was dedicated to breast cancer in 1997 and colorectal cancer in 1998, across both England and Wales. In England a further £10 million was allocated to lung cancer in 1999. As noted, further increases in funding for cancer were announced in the NHS Plan for England, set out in more detail in the Cancer Plan. There has, however, been some concern that these funds, which were genuinely intended for cancer services, have not always been used solely for this purpose. In 1999 to 2000 and subsequently, further funds for equipment and palliative care were made available through the New Opportunities Fund (NOF), arising from the National Lottery. Responsibility for funding cancer services in Wales transferred to the National Assembly in 1999. Since that time they have provided funding, including funds from NOF, specifically for cancer initiatives which support the Minimum Standards, as well as for buying equipment and developing networks.

1.21 A large national survey of cancer patients is currently under way in England, with the results due to be published shortly. This should provide important information about patients' views and experiences of acute hospital treatment. Combined with the results of the peer review exercise, this should allow both patients and professionals to compare services and focus sharply on local areas in need of improvement.

Some brief background about cancer

1.22 Cancer is a term covering many different conditions affecting different parts of the body in different ways. There are over 200 types of cancer: the most common affect one person in a thousand each year (Figure 1.1) (SD1). All cancers start in the same way by normal cells developing into abnormal ones. These abnormal cells multiply, clustering into a lump or tumour, which may or may not be harmful (or 'malignant'). Those which are malignant often damage surrounding organs and may spread and affect other parts of a person's body, forming new cancers known as 'secondary growths'. Malignant cancers tend to take very different courses and to have differing prognoses, depending on the part of the body affected.

1.23 The different forms of cancer, taken as a whole, are a major cause of ill health and death: roughly one quarter of all deaths in the UK arise from cancer. It is sometimes said that people have a 40 per cent chance of being diagnosed with cancer some time during their lives¹², but this statistic is misleading. Because cancer is generally much more common in older people, the chance of a diagnosis is small for many years, but then becomes much higher for those who live to age 65, and higher still for those age 75 or over.¹³ There are some exceptions, such as testicular cancer, which are more common in young people (SD1).

1.24 A diagnosis of cancer does not always - or even usually - mean imminent death. Survival rates vary enormously. For example, more than 70% of patients with breast cancer will be alive five years after diagnosis, but only 5% of patients with

Figure 1.1

Some types of cancer are much more common than others*

The most common types of cancer affect one person in a thousand each year

Number of cancers per 100,000 of the population, 1997

104.4	Lung
96.2	Breast
78.7	Colorectal (bowel)
56.1	Prostate
34.0	Bladder
24.9	Stomach
24.0	Non-Hodgkin's lymphoma
18.9	Oesophagus
18.0	Pancreas
17.0	All leukaemias
16.6	Ovary
11.4	Uterus
9.3	Cervix

* This excludes the most common form of cancer - skin - which generally involves far less complex treatment than others

Source: Data from ONS (1998)*

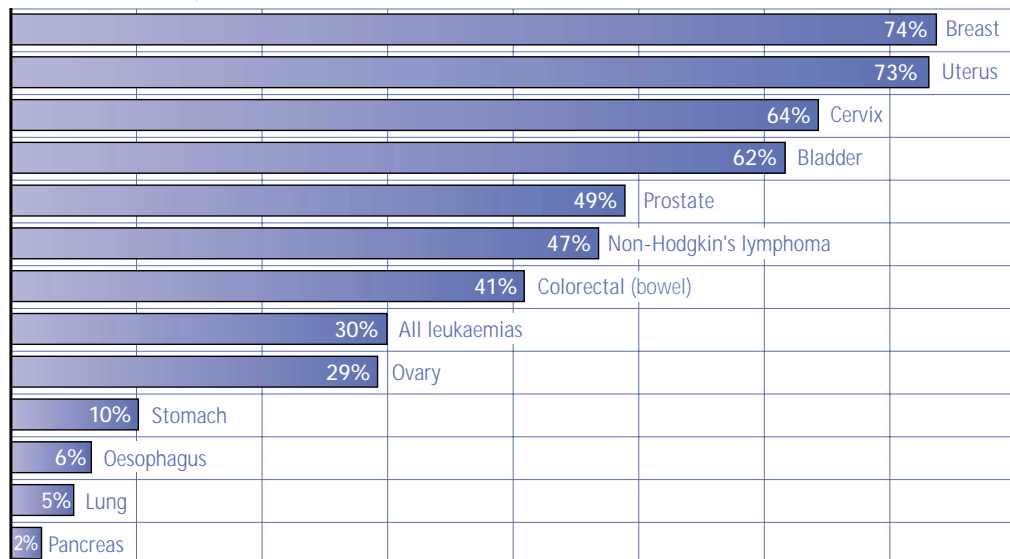
lung cancer survive that long¹⁴ (Figure 1.2). Survival from many cancers has improved over the years, although there are a few notable exceptions, such as lung cancer (Figure 1.3). Length of survival depends to some extent on the stage of the disease (how far it has advanced) when it is diagnosed. Chances of survival also vary between deprived and affluent patients, although this effect is more marked for some types of cancers than others (Figure 1.4).

Figure 1.2

Proportion of patients with cancer who survive five years or more (1991-93)

More than 70% of patients with breast cancer will be alive five years after diagnosis, but only 5% of those with lung cancer survive that long

Five-year survival (diagnosed between 1991-3)



Source: Data from Coleman et al (2000)¹⁵

1.25 Considerable attention has recently been drawn to research showing that UK survival rates for patients with cancer do not compare favourably with those in other countries of Europe¹⁹. There are, of course, several possible explanations for differences in outcomes, some of which are beyond the scope of this review, such as health promotion or early screening. In any case, the information refers to patients diagnosed more than 10 years ago and the situation may have changed since then. (SD1). This issue is clearly complex. Nonetheless, it is reasonable to assume that improvements could be made in treating and caring for people with cancer and this has served to alert the NHS and others to the need to look closely at treatment regimes and other issues.

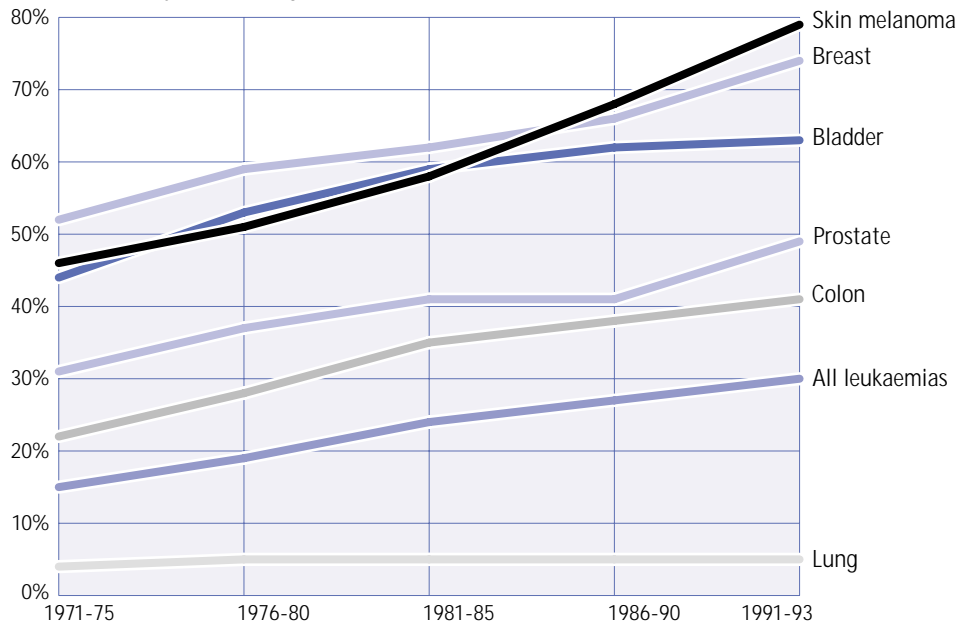
1.26 Services for people with cancer involve many disparate professional groups. General practitioners (GPs) have a central role, both in making the initial referral for tests and subsequently supporting patients, especially following treatment when they may need palliative care to relieve symptoms and provide emotional support (SD3). Patients are also likely to see a wide range of specialist consultants and other professionals, first for tests and then for surgical and other treatment. Specialist nurses are also important in providing advice, support and care throughout and

Figure 1.3

Trends in survival rates for common cancers (England & Wales)

Survival rates for most cancers are improving

Patients alive five years after diagnosis (%)



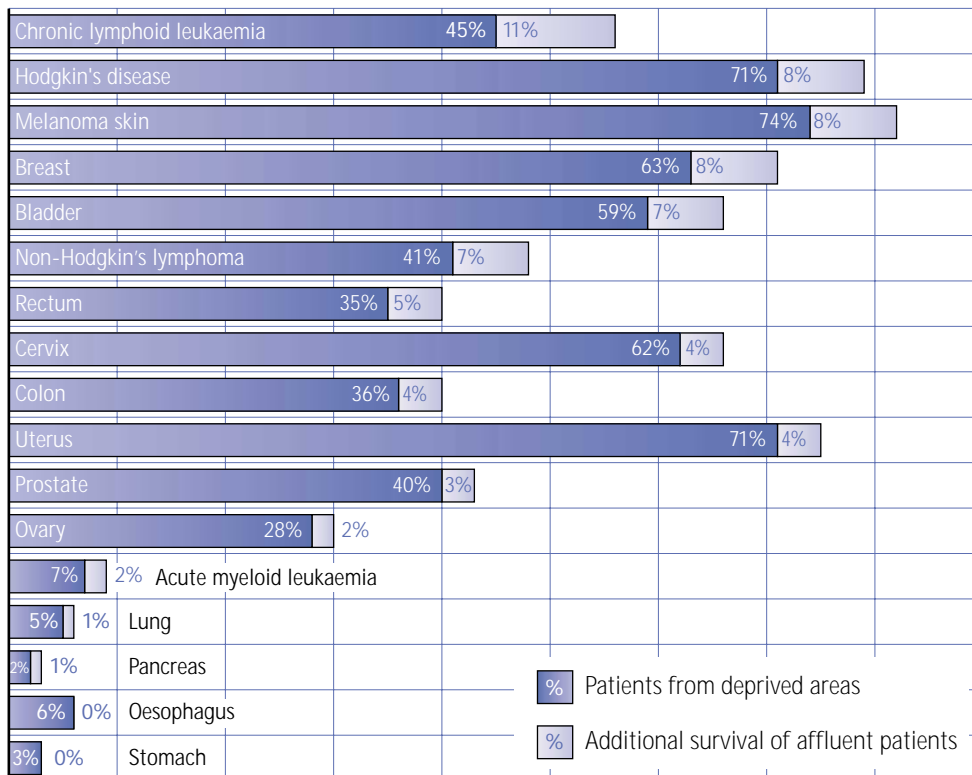
Source: Data in Coleman et al (1999)¹⁶ and Coleman et al (2000)¹⁷

Figure 1.4

Differences in survival between affluent and deprived patients

Chances of survival vary between deprived and affluent patients, although this effect is more marked for some types of cancers than for others

Patients alive five years after diagnosis (%)



The most common solid-tumour cancers have been plotted, along with the two most common leukaemias, and non-Hodgkin's Lymphoma and Hodgkin's disease

Source: Coleman et al (1999)¹⁹

district nurses play a key role in practical and emotional support. Many others outside the NHS, such as local authority social workers, may also become involved. Charitable organisations play a major role in providing palliative and terminal care.

1.27 The main stages involved in cancer diagnosis, treatment and care are set out in Figure 1.5. This illustrates the large range of people with whom patients come into contact, including doctors, nurses, other professionals, administrative staff, and so on. This can easily add up to 30 or more different people in the course of their care. The diagram also demonstrates the potential for patients to be confused and anxious, not to mention the many points at which delays or poor communication can occur. In many cases, the different stages are poorly co-ordinated and involve many separate visits to different departments within a hospital and sometimes to different hospitals.

Figure 1.5

Complexity of cancer care

The cancer system is complex, often poorly co-ordinated and can be confusing

There is no single pathway through the system – patients may move backwards and forwards between the stages in the table below. The lists under each heading illustrate the wide range of services and professionals that a patient may come into contact with

Stage:	Initial contact and referral	Diagnosis and options for treatment	Treatment and care	Palliative and terminal care	Monitoring and follow up
What might happen	<ul style="list-style-type: none"> • discussion of symptoms causing concern • routine screening tests • examination in A&E 	<ul style="list-style-type: none"> • tests: <ul style="list-style-type: none"> - scans – CT, MRI - x-ray - endoscopy - pathology (eg blood test) • information and advice • discussion of options 	<ul style="list-style-type: none"> • radiotherapy • chemotherapy • surgery • counselling/psychological support • information 	<ul style="list-style-type: none"> • palliative treatment eg non curative drug or radiotherapy treatment • therapy eg physiotherapy • counselling/psychological support 	<ul style="list-style-type: none"> • tests (scans, x-ray, pathology) • check up
Where	<ul style="list-style-type: none"> • GP surgery • A&E unit • screening service • home – may receive information/advice by post, internet or phone from voluntary or NHS organisations 	<ul style="list-style-type: none"> • hospital • GP surgery • home – information/advice from voluntary or NHS organisation 	<ul style="list-style-type: none"> • hospital • home • clinics • GP surgery 	<ul style="list-style-type: none"> • hospital • home • hospice • private hospital /nursing home 	<ul style="list-style-type: none"> • GP surgery • Home • Hospital outpatient clinic
Who may be involved	<ul style="list-style-type: none"> • GP • practice nurse • A&E staff • screening service staff: radiographer, nurse, doctor 	<ul style="list-style-type: none"> • oncologist • surgeon • physician • specialist nurse • radiographer • radiologist • pathologist • GP 	<ul style="list-style-type: none"> • oncologist (clinical or medical) • surgeon • specialist nurse • allied health professional (eg physiotherapist, dietician) • GP • palliative care nurse • palliative care doctor • social worker • psychologist or counsellor 	<ul style="list-style-type: none"> • palliative care nurse • palliative care doctor • social worker • community nurse • psychologist or counsellor • allied health professional (eg physiotherapist, dietician) • GP • radiotherapist • radiographer 	<ul style="list-style-type: none"> • GP • surgeons • physicians • oncologist • specialist nurse • pathologist • radiographer • radiologist

Patient centred care

1.28 In carrying out this review, it has been our explicit aim to understand patients' experiences of services. Patient centred care is usually defined in terms of the need for those professionals working directly with patients to give careful attention to their individual needs and concerns, offering choice where appropriate and full information on the implications of making certain decisions. This argues that patients should be given full attention by a doctor (or nurse or others), be treated with humanity and honesty and provided with as much certainty as possible about what they can expect. Sometimes, good continuity of care is also seen as part of this picture. All of this is at the heart of the principles of the Calman-Hine Report.

1.29 But patient centred care is about more than what takes place in an individual consultation. It should also mean that the whole cancer system is geared to meeting patient needs as a whole, with professionals working well together. When patients move from one place of care to another, for example, when they are discharged from hospital, the system needs to make sure that their many needs are met. This is particularly important in the case of cancer care where many different professionals may be involved.

1.30 It may help to illustrate this argument with an example. Under the usual definition of patient centred care, a breast surgeon should openly explore treatment options with patients, taking into account their particular preferences and personal circumstances. The surgeon should also be responsive to patients' needs for both information about the disease and a clear understanding of what the treatment process will involve, answering questions directly and involving a specialist nurse as needed.

1.31 Under the expanded meaning of patient centred care, the diagnosis and treatment decision should be communicated quickly to the patient's GP, so that he or she is aware of both the decision and what the patient has been told. This information also needs to be passed on to others likely to be involved, for instance if further tests will be needed or if treatment (such as radiotherapy) will take place at a different hospital. Records are needed at every stage, so that those involved can focus on patients' needs. While the way the consultation is handled is a personal issue, alerting others to its nature and impact is a matter of good systems. There is also a need to audit how this works in practice.

1.32 The findings set out in this review suggest that the system is not yet succeeding in delivering patient centred care under the expanded meaning of the term. Services are all too often provided without explicit thought as to how patients experience them or how different parts of the system might work better together. The new policies for cancer, the Cancer Plan and NHS Plan for Wales, having identified some of the key levers for change, will help. But they will not achieve substantial improvements for patients until there are better systems for coordinating and communicating across local networks, combined with significant changes in professional attitudes, relationships and behaviour.

Methods

1.33 This review is based on considerable new research, carried out jointly by the Commission for Health Improvement and the Audit Commission, across the eight regions of England and in Wales. First, because of a commitment on the part of both organisations to listen to the patient point of view, 15 focus groups (involving 85 patients with cancer) were undertaken to hear their experiences at first hand. These covered all English regions and Wales. Many key messages are reported here, but we have published a full report separately Supporting Paper 1 (SP1). The collection of this information was supplemented by a literature review, also being published (SP2).

1.34 Second, in order to learn more about how cancer services are organised and delivered, we visited one network²⁰ from each region in England and one in Wales, a total of nine, selected randomly. Because of this procedure, we can draw general conclusions from our findings. Within each network, we selected one or more of the different types of organisation involved and, for each, collected documents and asked for checklists to be completed. These included:

- health authorities and primary care groups or trusts (PCGs/Ts in England) and local health groups (LHGs in Wales)
- one radiotherapy-providing trust and two other acute trusts
- community trusts, where services are provided separately from acute trusts
- hospices
- community health councils (CHCs)

A list of all organisations visited can be found in Annex 4.

We also interviewed officers nominated by the English Department of Health and the English regional offices and the National Assembly for Wales.

1.35 Response rates for different types of information vary, because some organisations did not return all checklists and, moreover, those returned were not always complete. In some areas, two or more hospitals within the same trust returned only one form, whereas in other areas, they returned separate forms. This means that data can refer to only one hospital or to several within a trust.

1.36 As well as collecting this formal written information, we also interviewed around 1,100 different professionals across the nine networks using structured interview schedules. This included a wide range of consultants, health authority and hospital managers, cancer nurses and others. Many of their responses are summarised in SDs 2-10. This work was supplemented by nine focus groups with 57 GPs and another nine focus groups with 67 community nurses, in both cases covering all English regions and Wales, to discuss their perspectives. A report on these discussions is being published separately (SP 3). A number of other individuals and organisations were also visited to get their views and learn about innovative practices.

1.37 In order to examine the provision of radiotherapy more closely, we commissioned further analysis of information which the National Cancer Services Analysis Team had already collected on radiotherapy services in England and Wales for the Department of Health and the Welsh Office during 1998/9²¹. As part of that survey, data were requested from all radiotherapy facilities regarding all patients treated in the period April 1993 – March 1998, the date of their treatment, the site of their primary tumour, and the number of fractions of radiotherapy given. About half of the trusts were able to provide this kind of information. Again we are publishing our analysis separately.

1.38 Finally, we also commissioned the Centre for Health Services Studies at the University of Kent to analyse centrally collected statistics about patient activity within NHS trusts (the Hospital Episode Statistics (HES) system for England, and the Patient Episode Data/Wales (PEDW) system for Wales). Inpatient and day case activity for patients with a primary diagnosis of five types of cancer (breast, colorectal, genitourinary, gynaecological and lung) were extracted. For each type of cancer, activity by type of procedure was analysed for the years 1996/1997 to 1999/2000.

1.39 A full discussion of the research methods and procedures is provided in SP4.

The review

1.40 This review is structured around the experience of cancer from the patient's point of view. It begins with the process of getting a diagnosis (Chapter 2), then considers treatment issues (Chapter 3), followed by the provision of palliative and terminal care to patients (Chapter 4). As noted above, key issues for patient care are then drawn together at the end of these chapters in a section titled 'Hallmarks of a Good Service' and 'Some Questions Patients Might Ask'. We then turn our attention to more professional or policy related issues concerning the organisation and development of services (Chapter 5). Our final chapter reflects on recent progress of cancer services.

1.41 A central focus of our research was progress in the implementation of the Calman-Hine Report and a summary of key findings is provided in Annex 1. Milestones in the development of recent cancer policy are listed in Annex 2. Details of supporting papers and data are set out in Annex 3. The supporting data are referenced in the text as SD 1-10. Although we have tried to keep technical language to a minimum, a glossary sets out definitions of terms used.

1.42 All quotations are taken from the patient focus groups commissioned for this review, with the exception of one about bereavement care, which was taken from a report on patients and their families. They are intended simply to illustrate different perspectives, not to indicate the most common view expressed on any one issue.

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Getting a diagnosis and planning treatment

IT'S AS IF YOU'VE BEEN TO COURT and you're waiting for the jury to come back to find out whether you've got a death penalty or not.... They decide how long you're going to live for, basically...! (PATIENT, CAMBRIDGESHIRE)

2.1 For cancer to be diagnosed, people must pass through a number of stages. Having first recognised that there is a problem, almost all go to their GP, who must decide whether there is a possibility of cancer and refer them to a hospital consultant. Sometimes, another specialist or a health professional working in an accident and emergency department will make the initial referral. Tests will then be arranged to find out whether or not the patient has cancer. Patients then meet a cancer specialist to discuss the results and treatment options. Those who receive a diagnosis of cancer need more support and information as they move into treatment.

15

Initial visit to the GP

LOOK UPON MY GP AS A SORTING OFFICE. I want him to say "I don't know, but I'll jolly well send you to the person who does know...". That's what a GP is supposed to do. He can't know everything, can he?' (PATIENT, NORTH YORKSHIRE)

2.2 People can be reluctant to visit a doctor quickly when a symptom first occurs. This may be because they feel that their symptoms are not especially serious, i.e. that it is 'just a cough' or a 'vague pain' which may go away and in any case they may feel it is not important enough to bother the doctor about. Or they may suspect that something is wrong, but not want to hear that news. Although some reluctance may be unavoidable, the patients with whom we spoke felt that there is a need for better information on how to recognise symptoms so that people can be more aware of when to seek medical advice. In some areas, people can wait some time before getting an appointment with their GP.

2.3 Some patients are referred immediately to see a specialist or for tests, but sometimes the GP does not immediately suspect cancer, even though this is the eventual diagnosis. Among the patients we spoke to, most had been referred quickly. But a few had waited for six months or more for a referral and, not surprisingly, were very angry at the delay. Yet it is not easy for GPs to make an initial cancer diagnosis.

Many symptoms of cancer, such as a persistent cough or rectal bleeding, are the same as those for other less serious conditions. Sometimes GPs treat the symptoms and keep an eye on developments.

2.4 To compound the problem of diagnosis, typically, a GP does not see many new people with cancer in the course of a year. For example, it has been estimated that an average GP sees only two new cases of skin cancer and only one new case each of breast and colorectal (bowel) cancer per year. Furthermore, a GP will see a new case of leukaemia only once every five years, one brain tumour every seven years and one testicular cancer every twenty years¹. In contrast, they see symptoms that might imply cancer on most days, because people have coughs or rectal bleeding for other reasons.

2.5 Improving the accuracy of the initial diagnosis is clearly a priority. This is important both to speed up the process for those who do have cancer and to reduce the anxiety suffered by the many others referred for tests who turn out not to have it. One study suggests that for every patient subsequently found to have colorectal cancer, a GP has seen 300 people with possible symptoms and referred 45 of these to hospital² (SD3). This may be an extreme example because the symptoms of this particular cancer are especially common, but the general problem applies to many other cancers. Indeed, more resources are probably spent on checking patients who do not have cancer than on treating those who do (SD9).

2.6 The Department of Health has recently published guidelines for GPs to help with their referral decisions in England³ (SD3). Some of the GPs we spoke to welcomed these as a way of making their task easier, but others did not think they were much help. The extent to which these guidelines are used in practice is not clear, but some GPs admit that they do not use them, and some consultants suggest that they are not being used by GPs in their area (SD3). Constructive use should be made of audit on this issue, including feedback to GPs. There are plans to pilot referral guidelines in Wales, with a view to introducing them in 2002⁴. In the meantime, specialists must advise GPs on referral, and some local guidelines⁵ may have been developed in some areas.

2.7 The Department of Health is currently commissioning research to improve GPs' referral strategies. It will be important for the results to be well disseminated. But in the shorter term, GPs may need help to make the best use of existing cancer referral guidelines. This may not be easy, as some feel overwhelmed with guidelines for different diseases. Attention should be given to their layout and design, so that they are easy to follow. The principal symptoms of the common cancers have been summarised on a single sheet for use by GPs, although the impact on referrals is not clear as no audit information appears to be available. Computer support systems are also being explored. Training would help GPs to use the cancer guidelines as well as to become more familiar with them.

2.8 It is neither appropriate nor possible for GPs to become experts in the field of cancer, but closer working relationships with cancer specialists might help GPs to

refer patients most appropriately. Local lunchtime discussion sessions between GPs and consultants around cancer diagnosis have been welcomed in some areas. On an individual basis, greater use of the telephone and email might help GPs to explore the right course for patients whose situation is particularly unclear. The introduction of more Macmillan GP facilitators should also help GPs to become more familiar with cancer issues. Plans for new primary care lead clinicians for cancer (discussed in chapter 5) may, in time, also make a substantial difference.

Many patients with cancer are referred to hospital late or non urgently. This could be reduced by better use of referral guidelines and closer communication between GPs and cancer specialists.

2.9 Both practice and district nurses may also play a significant role at this early stage. In our discussions, they told us that they are often asked about incidental symptoms when seeing patients for some other reason. These nurses may also recognise symptoms when examining or registering patients. GPs should encourage nurses to be alert to the symptoms of cancer, as this might result in much earlier diagnosis for some patients. Some nurses would welcome training in recognising symptoms and handling subsequent discussions with patients.

17

Other routes to diagnosis

MY LEG SWELLED UP - that's what I went to the doctor's for. I was rushed in hospital as an emergency. It turned out I'd got a blood clot... In tests to find out why I had the blood clot, they found out that I had trouble with my ovaries.' (PATIENT, WALSALL)

2.10 Referral by a GP is not the only route to diagnosis (Figure 2.1). Some types of cancer, such as breast and cervical, may be detected through screening; up to one fifth of patients with these cancers are first discovered via routine screening programmes. We have not covered these programmes, as they were outside our remit.

2.11 In addition, up to two fifths of some cancers (especially lung and stomach) are initially found by a hospital specialist or an accident and emergency (A&E) department attended by a patient for unrelated reasons⁶ (SD3).

Referral to an outpatient clinic

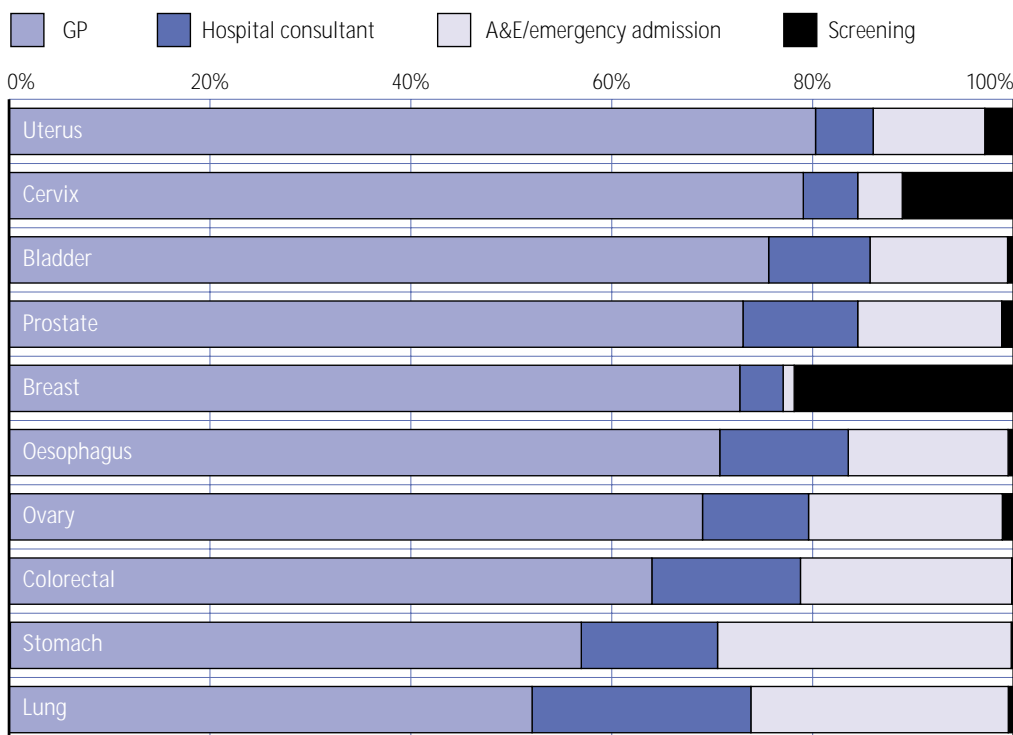
THE TROUBLE IS, MOST PATIENTS need the doctor to have a crystal ball - and that's the one thing he doesn't have.' (PATIENT, NORTH YORKSHIRE)

2.12 Once GPs suspect that a person has cancer, they will refer the patient to the local hospital outpatients' clinic for a consultation, with an indication of whether the situation is deemed 'urgent' or 'non urgent'. It is for this initial outpatient

Figure 2.1

Initial referral

Referral by GP is not the only route to diagnosis (England, 1997)



Source: Data from Spurgeon & Barwell (1999)⁷

consultation that the Government introduced a maximum two week wait for those whose cases are marked as ‘urgent’, first for suspected breast cancer but now extended to all cancers. Nearly all English hospitals are meeting this target in the case of breast cancer⁸ and both GPs and consultants commented favourably on this. It has also been announced recently that 92% of all patients with suspected urgent cancer are being seen within two weeks, although with some variation by trust⁹. This is a clear improvement: four years ago, a smaller proportion (although still a majority) of patients referred as ‘urgent’ were seen within two weeks, depending on the type of cancer (roughly three quarters of those with breast cancer were seen this quickly)¹⁰ (SD2). The situation in Wales is somewhat different: an initial standard that patients with breast cancer deemed urgent by a specialist be seen within five working days was found to be met in less than one third of cases¹¹, but nearly 90% were seen within ten working days¹². The standard was subsequently changed to ten working

days. In 2000, all minimum standards were revised and included the ten days target for all referrals deemed urgent by the specialist (SD2).

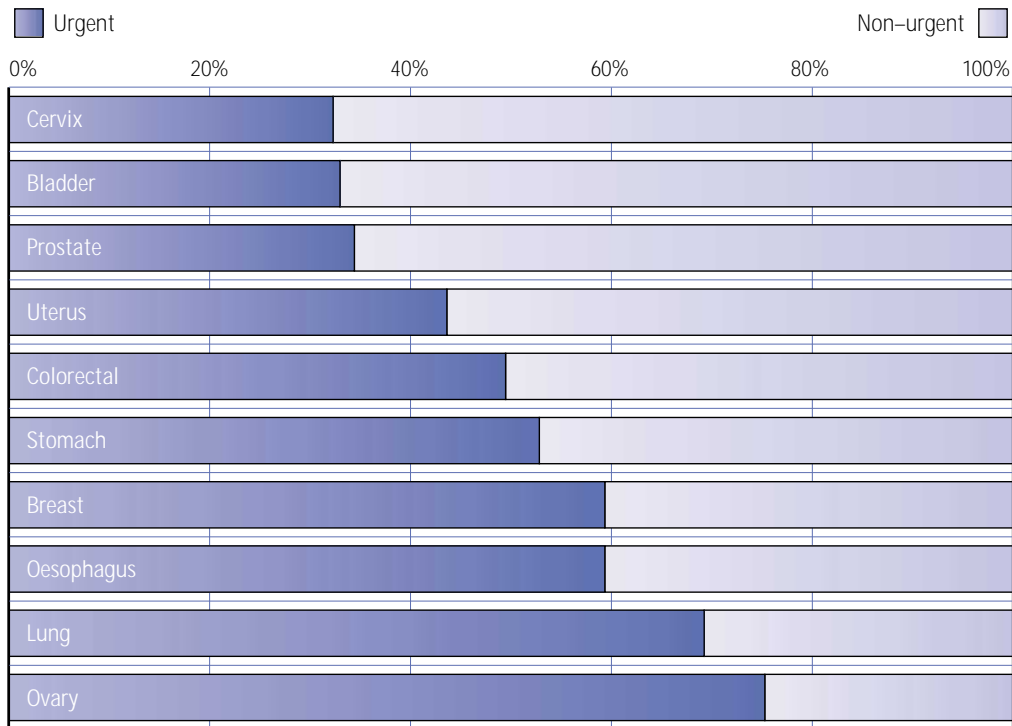
Although most trusts are meeting the Government’s two week waiting targets, especially for breast cancer, some have yet to achieve this.

2.13 Among the hospitals/trusts visited for this study, the majority reported that typical waits by cancer patients for an urgent outpatients appointment were up to two weeks. The exceptions were mostly for suspected prostate cancer, where a few trusts had

Figure 2.2

Cancer patients initially referred by their GP as 'urgent' (England, 1997)

About half of all patients subsequently found to have cancer were referred as 'non-urgent'

Source: Data from Spurgeon & Barwell (1999)¹³

typical waits of up to six weeks. Waiting times for non-urgent referrals were generally longer, with the majority of hospitals/trusts reporting normal waiting times of more than two weeks and often more than two months. The patients we spoke to had experienced wide variation in waiting times for the initial hospital appointment: some had been seen in less than two weeks, but others waited as long as eight or even twelve weeks (some of whose situations may not have been viewed as urgent).

2.14 Our interviews suggest that there is substantial variation in the use of an urgent designation across different forms of cancer. Indeed, other research suggests that approximately half of all patients subsequently found to have cancer were referred as non urgent; the disparity is particularly poor for patients with cervical, bladder and prostate cancer¹⁴ (Figure 2.2). In contrast, a recent local audit in one area of England found that roughly three quarters of all cancer referrals in the area were in line with national guidelines (SD3).

2.15 In our discussions with GPs, some admitted that they had tried to circumvent long waits by giving most patients an urgent designation or said they knew others who did so. Equally, some consultants felt that GPs were filling up clinics with people whose diagnosis was not urgent (or people without cancer at all), although others argued that GPs were too hesitant, delaying attention to patients later found to have cancer. There is a clear need to audit the way in which the referral guidelines are used and their impact on detection rates. Some of the suggestions mentioned above (see

paragraph 2.7) for closer working relationships between GPs and cancer specialists should also help.

2.16 Some delays at referral stage are due simply to poor communication procedures between GPs and hospitals, for instance in setting appointments. Projects set up by the Cancer Services Collaborative in England have given particular attention to this issue¹⁵. Developments include a central cancer referral office (which can set an appointment and immediately fax the date back to the GP) and computerised booking (which allows GPs to book patients directly into clinics). Indeed, the majority of trusts/hospitals have now introduced central referral offices to reduce waiting times and, in 2000-01, over three quarters of all urgent referrals were received within 24 hours¹⁶ (SD3).

2.17 A number of recent changes in the way cancer services are organised cut across traditional referral patterns from GP to hospital consultant. Whereas these were generally based on established relationships between individuals, the new arrangements often involve referring patients to the right service (such as a rapid access clinic, discussed below), rather than to an individual clinician. GPs need full information on where to refer patients if this is to work. Moreover, some may be reluctant to change their referral patterns if they feel it will reduce their influence over the course of a patient's care. Ensuring that GPs are well informed about the new system and demonstrating to them that it does work is essential.

Getting tests

THEY TOLD ME WHAT THEY WERE GOING TO DO, but they never told me why they were doing all these tests. I had every one down there - CT scan, outside, ovaries, up the back and everything.... I thought I had cancer all over me.' (PATIENT, KENT)

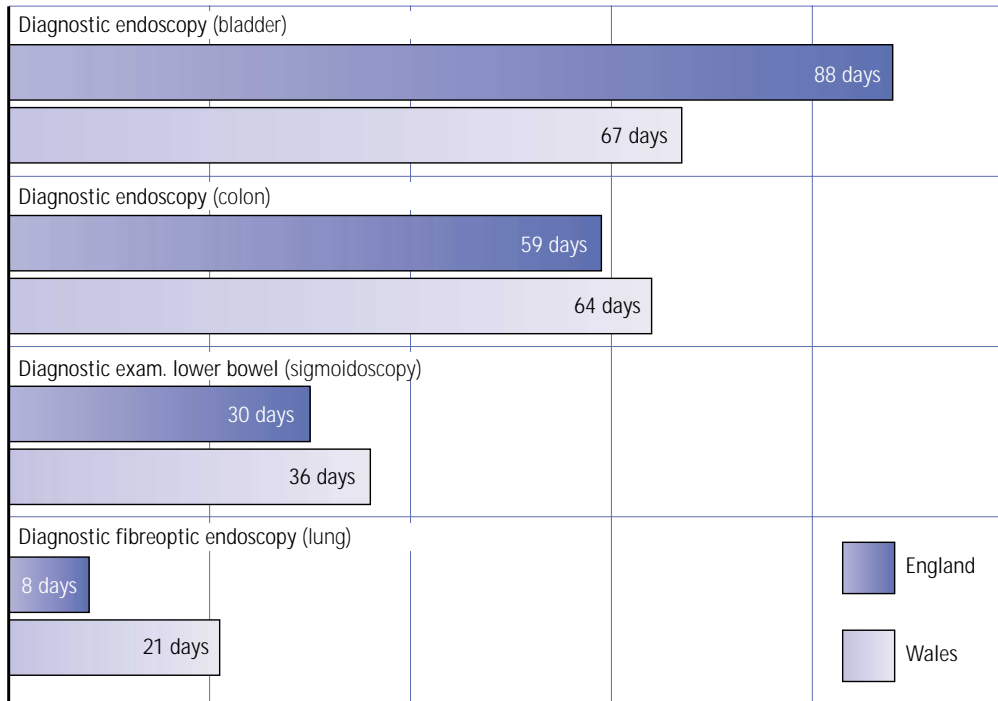
2.18 The first hospital appointment is only the beginning. Patients are then referred for tests, such as an x-ray, CT or MRI scan, ultrasound, endoscopy and various others, as deemed appropriate. Some patients have many different rounds of tests, because the initial results are not definitive or there is a need to investigate by different means. Different types of cancer differ enormously in the complexity of their diagnostic procedures. Some types of cancer cannot be diagnosed firmly until surgery has taken place.

2.19 In contrast to the speed with which patients obtain their initial appointment, many experience serious and unacceptable delays in getting the tests they need, depending on the test as well as the particular hospital. National data for different diagnostic endoscopic procedures, for example, show that average waiting times vary considerably between different types of test and cancer, but the waits are long for some patients. This analysis does not distinguish the urgency of waits (Figure 2.3).

Figure 2.3

Average wait for diagnostic procedures (1999-2000)

Patients have to wait for more than two months for some investigations



This analysis does not distinguish between the urgency of patients placed on waiting lists
 Source: Analysis of HES (England) and PEDW (Wales) hospital information by CHSS, University of Kent

2.20 Two hospitals/trusts visited reported typical waits for a barium enema of up to eight weeks, although others had shorter waiting times. Some consultants suggest that waits for CT and MRI scans are a problem for patients with some types of cancer. Indeed, the use of MRI scans is not as common as it should be. This can be a period of great anxiety and some of the patients we spoke to had paid for tests privately, as their GP had suggested that this would speed up the process. A few had waited over three months for a test (SD2).

2.21 The average waiting time varies considerably between different types of test and cancer, but the waiting times are long for some patients (although this analysis does not distinguish the urgency of waits).

2.22 Delays at this stage are normally caused by a lack of equipment, particularly for diagnostic imaging. For example, there is a five fold variation in the ratio of hospital patients to CT or MRI scanners between hospitals (Figure 2.4). This should be improving in both England and Wales. In the former, the New Opportunities Fund cancer programme has purchased 35 MRI scanners and modernisation capital will add another 50. There are also plans to purchase 50 additional CT scanners¹⁷. In Wales there are different

Delays in obtaining some diagnostic tests are still too long, in some cases because of shortages of equipment, such as scanners, and unimaginative use of resources.

funding criteria to England, but in 2001-2 1 MRI scanner will be replaced and 1 added, and 6 additional CT scanners will be provided¹⁸.

2.23 Our review suggests that resources may not always be used imaginatively. There are striking differences in the use of equipment: some hospitals scan more patients with one MRI machine than others do with three or four¹⁹. This may be due to the hours during which such equipment is used, the age of machines (older ones work less efficiently) or poor booking systems. In addition, some areas cannot recruit all the staff they need for the diagnostic process, such as radiographers and pathologists²⁰ (SD9). These variations are very worrying: trusts should closely monitor their performance and make sure that delays are not caused by inefficient use of equipment before investing in additional expensive machines (SD4).

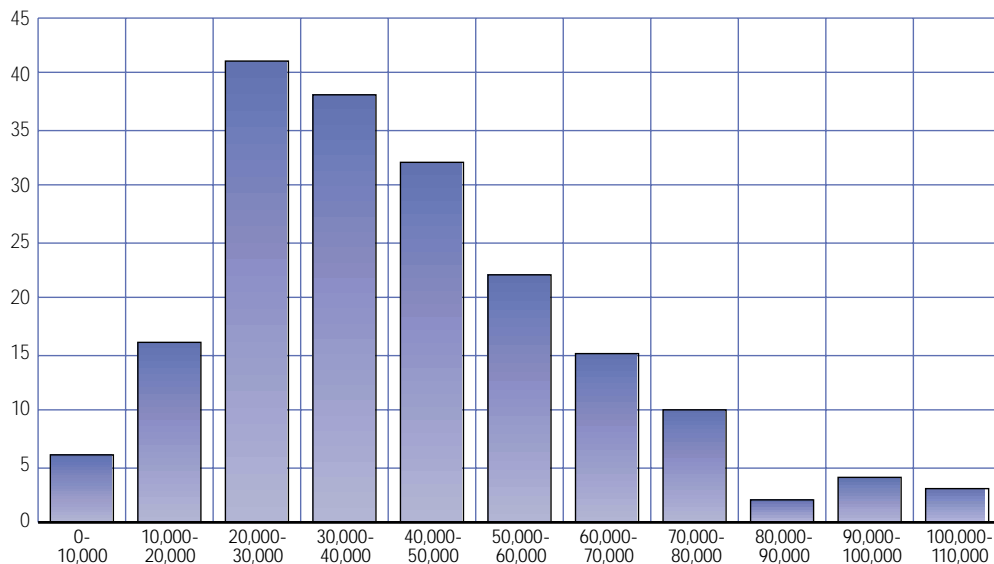
2.24 A number of approaches are being developed to reduce these delays. Rapid access arrangements have been developed in some areas. Papworth Hospital in Cambridge provides this kind of service for patients with suspected lung cancer, reducing the number of hospital visits required for patients as well as waiting times. Patients are also fully informed about the tests they need and are given written information on their treatment plan. This scheme was set up with the help of local GPs, palliative care and counselling professionals as well as hospital staff. One stop clinics are becoming common in many areas for some cancers, such as breast and colorectal. Only three of 23 hospitals/trusts visited did not offer this kind of clinic for at least some patients with breast cancer (SD2). Here, patients can be seen, tested and given their diagnosis on the same day. Such clinics are only possible

Figure 2.4

Hospital patients* per CT or MRI scanner in English trusts

Some trusts have five times more patients per CT or MRI scanner than others

Number of trusts



* Inpatients, outpatients and people attending A&E, weighted according to their relative use of scanners

Source: Data from the National Cancer Services Analysis Team, NHS Executive (North West) website²⁰

for the types of cancer where test results can be obtained quickly. In some areas, technical staff or specialist nurses have been trained to carry out tests. Similarly, some clinics have extended their working hours, including weekend working, to limit delays. Both these developments should be strongly encouraged elsewhere.

2.25 Our research with patients involved careful attention to their experience of tests. They suggested that these could be very unpleasant, occasionally painful and sometimes disturbing (such as the MRI scan), but they mostly felt that the people carrying out the tests were kind and considerate, offering comfort throughout difficult procedures. Many staff also offered full explanations of what they were doing and what to expect. Detailed information was seen as an important source of reassurance and was much missed when not provided. Whatever their experience, patients tended to be very pleased and relieved to be in the system at this point.

2.26 The period of waiting for test results is a period of great anxiety for patients and some found it difficult to understand why they needed to wait for results at all. It was seen as especially irritating where delays were felt to be caused by poor communication systems, such as test results not being in the right place at the right time. This is another area to which the Cancer Services Collaborative has given particular attention in England, for example, it has helped hospitals to develop pre-booked appointments for discussing test results (SD2). Every effort should be made to reduce patients' anxiety during the waiting period, for instance involving specialist nurses where possible to provide advice and support.

2.27 There is considerable concern among GPs and consultants alike, shared by the Cancer Services Collaborative²² and others²³, that the initial priority given to cancer patients is increasing delays for patients with other conditions, particularly in obtaining tests. Although we collected no hard evidence, most clinicians interviewed raised this issue. The impact is thought to be particularly marked for routine CT scans, where one area reported a 28 week wait for patients with diseases other than cancer. Some delay seems very possible, as it is the logical result of giving priority to patients with suspected cancer.

Discussing the diagnosis and treatment options

HE TOLD ME IN A VERY GOOD MANNER and told me very direct. He's very straightforward, really. It was all done very nicely. For the next couple of days, your head buzzes an awful lot, you tend to worry'. (PATIENT, DARLINGTON)

2.28 The pivotal discussion in the lengthy process of diagnosing and treating cancer is the one that takes place with a consultant following the diagnostic procedures. Here, the consultant must give what is commonly referred to as 'the bad news' and discuss the treatment options. A great deal of research has highlighted difficulties for patients as a result of consultants' poor communication skills at this point. Most of the patients we spoke to felt that their doctor had given them the

information with great sensitivity to their needs. Although learning about such a diagnosis almost always gave rise to fear and distress, the honest and caring way in which they had been told was said to help considerably.

2.29 There is a long way to go, however, before all patients have what they feel is a reasonable experience. The occasional patient was still given their diagnosis by telephone or letter, or even in a general ward where others could hear. Some were offered vague terms that they did not understand (such as a 'mass' or 'blockage'), leaving them uncertain about the diagnosis. Others were told too bluntly. Some found that their relatives were told first or given more information about the prognosis than they were.

2.30 This is also the point at which the proposed treatment is discussed. Patients vary considerably in the amount they want to know about the disease or be involved in treatment decisions. The patients we spoke to stressed that they were generally

given good information on the type of treatment proposed for them and they particularly welcomed sketches of the affected area. Most were not offered any choice of treatment, but were content with this as they had confidence in the expertise of their consultant. Furthermore, they did not think there was a great deal of choice due to the need to act quickly. A few, however, said they would prefer more active involvement in the decision, including serious consideration to having no

treatment at all (SD2). Some voluntary organisations have provided information on general treatment issues, such as the Cancer Research Campaign²⁴.

2.31 Because each patient's circumstances, concerns and wish for information and involvement are different, training programmes are needed to provide consultants with the skills to understand a person's needs. Only one quarter of the lead consultants interviewed had any training in handling these issues; many of those we spoke to argued that they found their own experience a useful guide. But the situation is inevitably delicate and can be complicated by an underlying ambivalence on the part of some patients, making it difficult for them to articulate how much they want to know (SD2). The Cancer Plan makes a commitment that, by 2002, a pre condition of qualification for a health professional will be that they are able to demonstrate competence in communicating with patients²⁵. This will be for new consultants only, but advanced communication skills training will form part of continuing professional development programmes.

2.32 Patients generally say that they like to have someone, such as a close family member, with them at the time of this discussion. This is partly for emotional support, but it also provides valuable back up for asking questions and taking in necessary information at a time when their mind is not altogether clear. Although this is not always possible, patients should be told explicitly that their husband, wife, family member or friend would be very welcome at the consultation.

Patients report that they were told of their diagnosis with great sensitivity, but occasional examples of unacceptable practice were noted.

2.33 Patients also welcome the increasingly common arrangement where a specialist nurse (known as a clinical nurse specialist or CNS) sits in on the discussion and then talks with them afterwards. This offers them time to take in the implications of the diagnosis and raise questions that did not come to mind during the consultation. Most specialist nurses interviewed had been specifically trained in handling discussions of this kind; where they are not available, outpatient clinic nurses sometimes fill this role.

Clinical nurse specialists are a valued source of information and support. Unfortunately, their numbers vary from place to place and according to the type of cancer.

2.34 These specialist nurses usually specialise in one type of cancer, offering advice and support to patients and their families throughout their cancer experience. (SD8) They provide continuity at a time when the patient will come into contact with a wide range of people, and are very popular with patients. But there is great variation in their employment: most hospitals/trusts visited employed one or more CNSs for breast cancer, but only a small minority had one for gynaecological or stomach cancer (Figure 2.5).

2.35 Where they do exist, the workload, responsibilities, grades and accountability of these nurses vary considerably. Some nurses interviewed felt that patients did not get enough of their time. Systems for managing and supervising the nurses are not

Figure 2.5

Clinical nurse specialist posts for different cancers

Most hospitals visited employ at least one CNS for breast cancer, but only a small number have one for gynaecological or stomach cancer

Number of trusts/hospitals with one or more CNS None

18	Breast	Breast	3
16	Colorectal	Colorectal	6
14	Lung	Lung	8
10	Prostate & bladder	Prostate & bladder	11
9	Head & neck	Head & neck	13
6	Gynaecological	Gynaecological	15
5	Stomach etc	Stomach etc	17

Source: CHI/AC visits to 19 trusts/hospitals in England and Wales (2000/01)

always well developed, and working relationships with consultants vary. In most areas, there are difficulties in maintaining cover, for instance, for periods of leave. Networks should agree the critical stages at which these nurses need to be involved and develop local arrangements so that all patients with cancer can benefit from them. It may not be possible to develop specialist nurses for every kind of cancer, but all patients should have access to someone with the equivalent skills and competencies. Attention should also be given to their workload to ensure greater consistency.

26 2.36 It is becoming increasingly common for patients' medical, social and psychological needs to be discussed at this point by a multidisciplinary team (MDT). These teams consist of the doctors likely to be involved in the patient's treatment, specialist nurses and occasionally others, such as medical trainees or therapy radiographers. How these teams are used depends on the type of cancer, but they are almost the norm for common cancers, such as breast, lung, colorectal and others. However there remain some key types of cancer for which they are not well developed. Most MDT meetings do not involve patients, but in what is known as a joint or combined clinic, two or more specialists (and others, such as specialist nurses) meet directly with patients to discuss the prognosis and treatment plan. Some patients welcome the chance to meet everyone who will be involved in their care, but others can be overwhelmed and feel insecure, especially if a lot of people are involved. These teams are discussed in more depth in Chapter 3 (SD5).

2.37 Whether patients see only one consultant at this point or the whole set of people likely to be involved in their care, they should receive as much clear information as possible about what is likely to happen at each known step of the process and when. This is not easy, because there are likely to be many different professionals and departments involved and the timing of treatment itself may not be clear. The Cancer Services Collaborative has made some strides in this direction.

2.38 Two examples of services which place a high premium on helping patients to understand what is happening in their care deserve attention. The Integrated Breast Care Pathway, located within Salisbury District Hospital, has mapped out the whole plan for a patient's care, with referral guidelines for GPs, immediate appointment booking and a one stop clinic for tests and diagnosis. For treatment, there is a pre admission clinic run by nurses and careful discharge planning. Patients are offered information about the clinic, a personal treatment plan and a diary. A breast care nurse is involved at all stages.

2.39 Measham Medical Unit in Derbyshire has approached this issue by developing patient held records, started as soon as a person receives a diagnosis of cancer. This includes information on all professionals involved in the patient's care, and provides space for patients to write down what they have been told about their disease, medication and treatment as well as questions they want to ask. All professionals working with the patient then add to the record when they meet (SD2).

2.40 Once the diagnosis is clear and the treatment plan has been decided, it is essential that information is passed quickly to the patient's GP. This should include the diagnosis, prognosis, treatment plan and treatment options and what the patient (and family) have been told. It is commonly argued that there are not enough secretarial staff to do this quickly and there are difficulties in attracting such staff. Both the new English Standards and the All Wales Minimum Standards require GPs to be told about a cancer diagnosis by the end of the following working day²⁶.

2.41 There has also been some recent attention to arrangements for getting treatment, with the introduction of pre booking at the time of diagnosis to overcome delays that might happen at this stage. Most of the hospitals/trusts visited had developed this kind of booking system for some or all kinds of cancer, most commonly for gynaecological and breast cancer and less so for prostate cancers. The system was also more common for surgery than for chemotherapy or radiotherapy (SD2). Such pre booking is important for patients, as it reduces anxiety and inconvenience, as well as offering greater certainty about what is to happen. All trusts should be able to make these arrangements.

Subsequent reflection and information needs

LACK OF CONTROL IS THE WORST THING about the whole experience...All of a sudden everything's out of your hands. The opportunity to have knowledge and to act on it – or to discuss it as and when – gives you that degree of control back again! (PATIENT, NOTTINGHAM)

2.42 Patients can find it difficult to take in all the details of their diagnosis, prognosis and impending treatment during the first discussion with the consultant, even where the patient spends some time afterwards with a specialist nurse. Patients clearly need opportunities to ask questions later. Some of those we spoke to liked the idea of a formal letter sent after the consultation or a tape recording of the interview with the specialist to remind themselves later about what was said.

2.43 Most patients say they prefer talking to someone, rather than formal written information. But some of those we spoke to felt that written information was also helpful as they could read and reread it as the need arose. This could also prove valuable for patients' families, to help them to understand what the person with cancer is experiencing. Some had obtained leaflets directly from cancer organisations or, more rarely, the internet. We found that hospitals/trusts varied enormously in the information provided for patients; a few had a general information centre, and those providing radiotherapy often had a cancer information centre, but others provided only a few relevant leaflets or none at all (SD2).

2.44 The new networks should have an information policy to ensure consistency of access to good quality information. This should include making efforts to find the

best way of communicating with those whose first language is not English or Welsh, or who cannot read because of problems with sight or other reasons. There may be a need for leaflets to be translated into other languages, but other avenues might also be explored, such as tapes (in English, Welsh and other languages), interpreters, or closer working with local community groups.

2.45 After hearing their diagnosis, some patients choose to return to their GP for a general discussion and advice. The GPs we spoke to felt they could provide a valuable listening ear, but were reluctant to provide direct advice, as they were not sufficiently up to date on treatments. They also noted that they were often hampered by lack of information from the consultant about the patient's situation. This could leave GPs feeling powerless to help and was also felt to serve the doctor-patient relationship badly, as it began this phase of care on a bad note.

2.46 A delicate question at this stage is whether patients should be helped to think through whether it might be appropriate not to take forward active treatment. Some people, for instance, might not wish to undergo frequent treatment with highly unpleasant side effects just to gain a few extra weeks or months of life, as can be the case for some forms of chemotherapy. Some GPs felt that they had an important role in discussing this issue with patients. Specialists, they argued, can be predisposed to treat patients, whereas a GP's knowledge of a patient's history and circumstances allows them to take a more considered view. It is not clear how many patients would refuse treatment – only two of those we spoke to actually did so – but it should be an option open to them. Both GPs and specialists need to communicate honestly to patients both the benefits and costs of treatment from their point of view.

Patient centred care

AFTER THE DOCTORS HAD TOLD THE FACTS and explained the procedures, I found it particularly valuable to have one of the specialist nurses there [to] put it in more easily understood terms and in a very personal way... The nurse can talk you through some of the practicalities, you then can open up because you've had a little time to assimilate it! (PATIENT, CAMBRIDGESHIRE)

2.47 To what extent can the whole process of obtaining a diagnosis be said to be properly centred on the needs of patients? We found tremendous commitment among all those involved to making the process as quick and as sensitive to patient needs as possible. Patients themselves say that consultants have become very alert to their wishes and more open with information about their situation. Specialist nurses were warmly welcomed and those involved in carrying out tests were appreciated for their kindness.

2.48 But it cannot readily be said that the process, taken as a whole, is designed to give greatest priority to a patient's needs. First, with some exceptions, the process is

not always quick. Some patients experience delays in getting an initial referral from their GP. Although the time to their first hospital appointment is reasonably short for most patients, considerable delays arise in obtaining tests and making further appointments to discuss the diagnosis and treatment options. These periods of waiting are particularly difficult for many patients as they tend to fear the worst.

2.49 Second, actually going through the process is not easy for patients at a time when they are inevitably anxious. Before they have even been treated, they will normally have experienced at least four appointments (with a GP, an outpatients' clinic, a department where tests are carried out and a discussion about diagnosis and treatment) and many will have had more, for instance if they needed more than one test. At those appointments, they will have had contact with what may be seen as a dizzying number of people, from generalists such as GPs to specialists in diagnosis and a range of cancer specialists, both nurses and doctors.

2.50 Third, those involved are not always good at communicating relevant information to patients or gauging what a patient wants to know. Patients rarely seem to be actively involved in deciding what is to happen to them. Equally worrying, professionals are not always good at communicating with each other quickly and clearly. Important information, such as what a patient has been told, can often be missing. This is not simply an issue of good administration. Patient care is affected if the specialist lacks key information from the GP or vice versa. While the development of multidisciplinary teams should help all those involved to know what each other are planning, there is still a long way to go, especially for those who are not part of the hospital system.

Getting a diagnosis and planning treatment: Hallmarks of a good service and questions patients might ask

Hallmarks of a good service

- GPs use the Cancer Referral Guidelines where available and audit their referrals
- Patients deemed to need urgent attention get their first hospital appointment within two weeks.
- Hospitals organise tests at a time to suit patients and to avoid unnecessary delays.

Questions patients might ask

- What are you referring me for?
- How quickly will I be seen? Are you referring me as 'urgent' or 'non-urgent'?
- Will the timing of the tests be convenient for me?
Where will they be carried out?
Will I need to visit several departments?
How long will it be before I have all the tests?

Hallmarks of a good service

- Patients are told about the nature and purpose of tests, when they will receive the results and who they will receive them from.
- Patients experience minimum discomfort and receive good information and support during tests.
- Equipment for tests is used efficiently to minimise delays for patients
- Referrals are made to the appropriate cancer specialist
- Test results are passed quickly to the specialist who will be seeing the patient.
- Patients are encouraged to bring someone with them to discuss the diagnosis and treatment options
- Those discussing the diagnosis with patients are trained in communication skills.
- Someone is available to discuss the diagnosis and its implications after the initial interview.
- GPs are told quickly about a patient's diagnosis, prognosis, proposed treatment and what the patient has been told.

Questions patients might ask

- What are the tests for?
How many will I need?
Who will give me the results and when?
- Will the person doing the test look after me while it is being done?
Will they tell me what to expect?
- What times are available for me to have my tests, for instance could they be done in the evening?
- Is the doctor I will be seeing a recognised cancer specialist?
- Will the doctor have all my test results?
Will the meeting be for diagnosis or treatment?
- Can I bring someone with me to discuss the diagnosis and treatment?
- Will the consultant understand my concerns and give me time to ask questions?
Will a specialist nurse be there to help me?
- Who can I telephone when I think of questions later?
Can I make another appointment to see someone in person?
- Will someone have passed on the diagnosis and what is planned to my GP?
How quickly will this happen?

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Treatment and care

IF SOMEONE'S HOUSE IS ON FIRE, everyone panics, but immediately the Fire Brigade appear, they all stand back with a sigh of relief – the experts are here. And it's very similar – once you get into hospital and you have the specialist there, there's this weight lifted off you, you know that you're in good hands.' (PATIENT, NORTH YORKSHIRE)

32

3.1 Chapter 2 has taken the patient through the processes of initial diagnosis, testing and first outpatient appointment. Here we turn our attention to treatment. This varies according to the needs of each patient but usually includes some combination of surgery, chemotherapy or radiotherapy. Three issues are likely to matter most to patients at this point:

- the speed with which treatment starts
- the nature of the treatment
- the care and support that they are given throughout

The speed of treatment

ANY OTHER COMPLAINT, YOU'RE WAITING AGES, AREN'T YOU. I got the view that this Government's ordered that cancer, you've got to get cracking - you're a special case all the time with cancer.' (PATIENT, DERBYSHIRE)

3.2 Despite most patients' concern to act quickly, there are many sources of potential delay between a patient first noticing a possible cancer symptom and the start of treatment. We have already discussed delays in getting a first outpatient appointment following referral by the GP as well as delays in obtaining required tests in Chapter 2. Here, our focus is the wait from when the patient is told the diagnosis and need for treatment to the actual start of treatment. This serves as a critical measure of hospital performance. Our research asked hospitals about waiting times for the different forms of treatment for particular types of cancer. In some areas, patients deemed to need urgent treatment can expect to wait for more than four weeks on average for it to start (Figure 3.1).

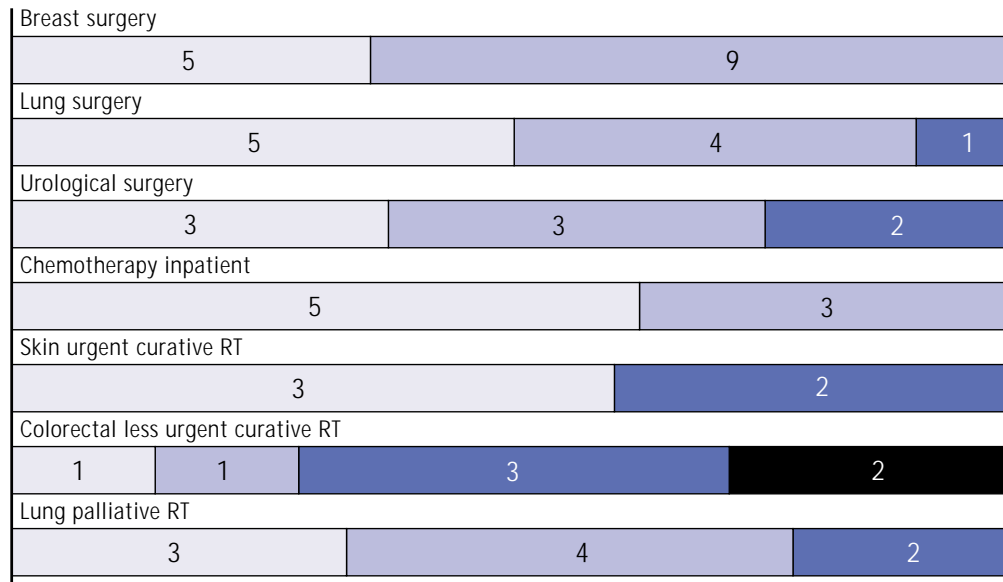
3.3 Our research found that waiting times for surgery for patients with breast and lung cancer are relatively short, but patients needing prostate surgery tend to wait

Figure 3.1

Typical waiting times post diagnosis for patients needing urgent treatment

In some areas, patients deemed to need urgent treatment can expect to wait for more than four weeks on average for it to start

Typical waiting times for selected services



Note: The numbers printed on each bar are the actual number of trusts with these waiting times. The bars have been drawn to a percentage scale to allow for comparisons

Source: CHI/AC site visits to 16 trusts/hospitals in England and Wales (2000/01)

much longer. Five hospitals/trusts treated breast cancer patients within two weeks and the other nine did so within four weeks. Most also reported typical waiting times for lung cancer patients of up to four weeks (of which half were seen within two weeks), but one reported regular waits of up to eight weeks. In the case of prostate cancer, two out of eight hospitals/trusts reported that patients were often waiting up to eight weeks. While some specialists felt that the typical delay had no clinical importance, only a minority of urological consultants felt so (and lung and colorectal consultants were split). But whatever the clinical relevance of delays, they can add greatly to the patient’s anxiety (SD2).

3.4 For inpatient chemotherapy, typical waits of up to four weeks were reported by three out of eight hospitals/trusts. Most consultants felt that these waits were satisfactory, with some variation according to the type of cancer (SD2). In some areas where there was no dedicated oncology unit, treatment was occasionally postponed due to pressure on beds from emergency medical admissions. We did not collect specific data on waiting times for outpatient chemotherapy.

3.5 Waiting times for radiotherapy were found to be a serious problem in some areas, varying with the type of cancer and urgency of need. Waits for potentially

The time patients wait before receiving treatment varies from one area to another; in some places and for some cancers, patients wait for more than a month after referral for urgent treatment.

curative radiotherapy for skin cancer (urgent) were up to eight weeks in two out of five hospitals/trusts providing data (although professional standards suggest that urgent radiotherapy should be provided within 48 hours). For palliative radiotherapy for patients with lung cancer, only three of nine hospitals/trusts reported waits of less than two weeks (the maximum wait suggested by professional standards). Finally, waiting times for less urgent radiotherapy for patients with colorectal cancer were typically up to eight weeks in three (and more than eight weeks in another two) out of seven hospitals and trusts. (the maximum wait suggested by professional standards being four weeks) (SD2). Other information shows that in 1998, one third of non urgent curative radiotherapy, one quarter of palliative radiotherapy and 8% of urgent radiotherapy was provided outside acceptable professional limits¹.

3.6 The National Cancer Plan in England (2000) is committed to reducing patient waits for treatment. This includes, for example, a maximum two month wait between an urgent GP referral and treatment and a maximum one month wait from confirmed diagnosis to treatment for all cancers. But some key standards do not have to be met until 2005 and they do not resolve the problems of patients now. The equivalent plan for Wales is also committed to reducing waiting times, and there is also a specific target for treatment waits (no more than 15 working days following diagnosis) for patients with breast cancer².

3.7 Whatever the anticipated waiting period for treatment, patients should be told what to expect. All waiting periods are a source of much anxiety and information can help to reduce this. Treatment delays should also be monitored and, of course, reduced wherever possible. Sometimes this will be through improvements in access to chemotherapy and radiotherapy as discussed below. But it may also involve making sure that patient delays do not occur due to staff leave, for instance on bank holidays or for training courses. Such arrangements should be planned with patients from the start.

The nature of cancer treatment

THEY WERE SAYING I WAS USING THE WARD LIKE A FILLING STATION, I'd had so many blood transfusions.' (PATIENT, SWANSEA)

3.8 As well as speed, there are questions about the level and quality of provision for each of the three main modes of treatment – surgery, chemotherapy and radiotherapy. As most patients receive more than one type of treatment, there are also issues concerning the integration and coordination of the whole treatment programme. Lastly, when treatment is over, additional arrangements must be made to make sure that discharge and follow up progress smoothly.

Surgery

I GOT THE SENSE THAT I WAS WITH SOMEONE WHO KNEW WHAT THEY WERE DOING. He was the person who did the operation, who had the reputation on the ward of being a bit of a stickler. Everybody said if anyone was going to do the operation, they'd choose him.' (PATIENT, NOTTINGHAM)

3.9 Our visits to hospitals/trusts included attention to views on the adequacy of provision of surgery. Most consultants were satisfied with their access to theatre slots and beds for patients, with some variation by cancer type. Satisfaction was least high among urological consultants. In general, we were told that every effort was made to provide quick admission to surgery for patients with cancer, although this could have a knock on effect for others.

3.10 A central recommendation of the Calman-Hine Report was for greater specialisation among those treating patients with cancer. This has been followed up in the subsequent expert group guidance (often referred to as COG guidance), which followed publication of the report³. Cancer surgery was traditionally undertaken by general surgeons, but there has been a tendency for some time toward specialisation in particular body systems (upper gastro intestinal, kidney and urinary tract, etc.) Such specialisation is increasingly being taken one step further, with these surgeons sub specialising in cancer surgery and sometimes a smaller sub-set, such as ovarian cancer. This kind of specialisation was fairly uncommon in 1995, except for breast surgery. Most trusts now claim to have identified lists of sub-specialists for all types of cancer (SD6).

3.11 But what is claimed is not necessarily what happens in practice and many patients are clearly being operated on by non specialists, even where a specialist is available. Some of this is inevitable. For some types of cancer, surgery may on occasion have to be carried out in an emergency, by the surgeon on duty rather than the specialist in the area. Moreover, there is not always enough work in the case of rarer cancers in smaller hospitals for sub specialisation to be practicable. But such reasons cannot explain the major variations observed. For example, while at one hospital visited, a single surgeon carried out more operations for colorectal cancer than all other colleagues together, at another similar hospital, the workload was shared evenly between several surgeons (Figure 3.2) (SD1&6).

3.12 The key question is whether sub specialisation is important in every circumstance. The principal argument rests on the view that specialist surgeons achieve better results, but there is evidence to support this only for some types of cancer. The benefits of sub specialisation have been clearly demonstrated in studies of ovarian⁴ and colorectal cancer⁵, and expert group guidance also recommends it for breast and upper gastro

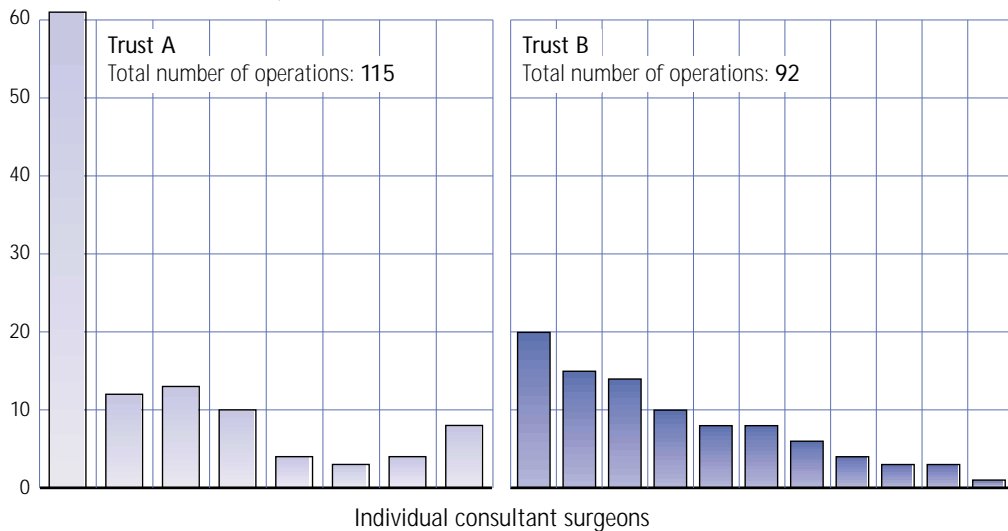
Although there is evidence of increasing specialisation by surgeons and non surgical oncologists, many patients are being treated by non specialists.

Figure 3.2

Contrasting degrees of sub-specialisation at two similar trusts.

At one hospital visited a single surgeon carried out more colorectal cancer operations than all other colleagues together, at another the workload was shared more evenly

Number of colorectal cancer operations (1999-2000)



Source: CHI/AC site visits (2000/01)

intestinal surgery⁶. Such research has not been replicated for all cancers, however, and its universal applicability is uncertain. Indeed, some surgeons cite the lack of evidence as their reason for not specialising. They may also have difficulty with the limit it imposes on their scope for professional development.

3.13 The benefits of specialisation may differ according to the nature and incidence of particular cancers. Where benefits are clearly proven, trusts should make sure that specialisation is in place, but where it is not, a degree of caution is in order, as the resource implications are significant. More research is needed here. But trusts should also collect evidence about specialisation in practice and take steps to increase it, where appropriate. Audit information should be available to patients, including the degree of specialisation by the consultants who may be treating them. The West Midlands region publishes a list of consultants and their sub specialisations.

Chemotherapy

THEY EXPLAINED THAT THERE ARE ABOUT 50 DIFFERENT CHEMICALS in chemotherapy, and each dosage is tailor made to the individual person, which is so reassuring! (PATIENT, CAMBRIDGESHIRE)

3.14 The use of chemotherapy, introduced roughly 30 years ago, has grown dramatically since that time (SD9). It involves an intravenous infusion (or 'drip') of drugs, an injection or, less frequently, pills that reduce the rate of growth of cancers,

sometimes completely. About half of all patients with cancer now receive some chemotherapy, varying with the type of cancer and the practice of individual consultants⁷. Aside from clinical reasons, this variation arises from lack of clear guidance for some cancers as well as lack of familiarity with the guidance that is available. Although there was some media concern that taxanes for patients with breast or ovarian cancer were not equitably prescribed across all areas, few consultants interviewed felt this to be a problem, following the publication of guidelines by the National Institute for Clinical Excellence (NICE)⁸ (SD4).

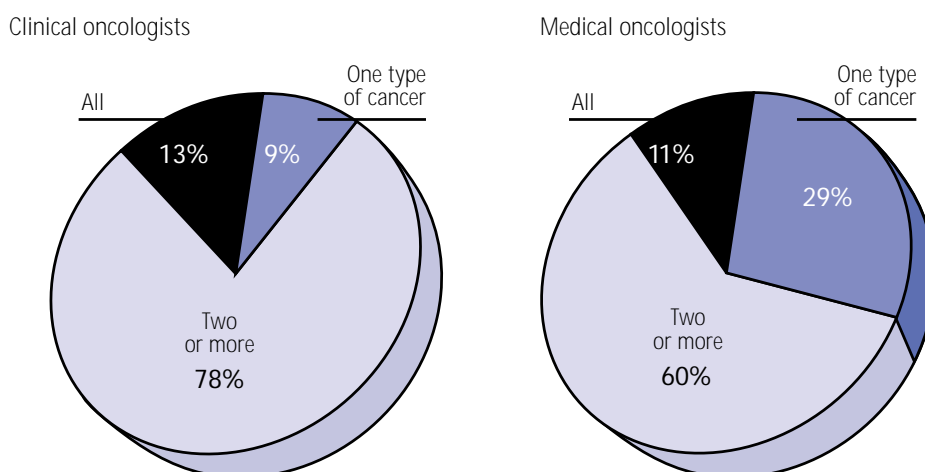
3.15 Chemotherapy is sometimes prescribed by specially trained medical oncologists, but is more commonly prescribed by clinical oncologists, trained both in radiotherapy and chemotherapy. This is because many hospitals do not have a medical oncologist; almost one third of networks do not have one at all and some large cities have only one⁹. From interviews with both types of oncologist, most felt that there was little variation between themselves and their colleagues in prescribing treatment for similar patients, mainly because there were agreed protocols which were felt to be followed. Yet other information suggests that a minority of trusts do, in fact, have agreed chemotherapy guidelines (SD4). Trusts should audit their practice to provide some information on this issue.

3.16 Like surgeons, both medical and clinical oncologists (sometimes known as non surgical oncologists) can also specialise in individual types of cancer (SD7). Most medical and clinical oncologists see patients with more than one type of cancer; about one in ten are total generalists (Figure 3.3). In the networks studied, the extent of specialisation varied and did not relate to the number of oncologists in a hospital.

Figure 3.3

Sub-specialisation by medical and clinical oncologists

Most medical and clinical oncologists see patients with more than one type of cancer; about one in ten are total generalists



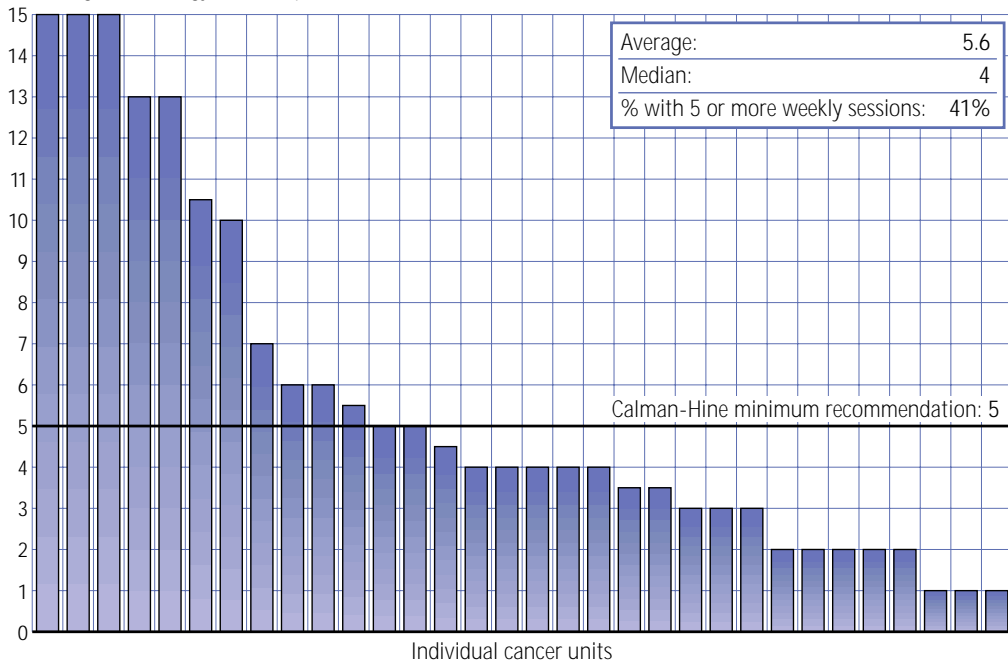
Source: CHI/AC site visits to 18 trusts/hospitals within England and Wales (2000/01)

Figure 3.4

Non-surgical oncology sessions at cancer units

More than half the units fail to meet the Calman-Hine minimum recommendation of five (3½ hour) sessions a week

Non-surgical oncology sessions per week



Source: CHI/AC site visits to 33 trusts/hospitals in England and Wales (2000/01)

The recent standards for cancer services in England propose that clinical oncologists should specialise in no more than two types of cancer and deal with two others¹⁰. This should be monitored by trusts.

3.17 Many medical and clinical oncologists also provide services at cancer units outside of their hospital or trust (outreach services). The Cancer Report recommended a minimum of five sessions (each session is a three and a half hour work period) for each unit, but in fact more than half of the units visited do not meet this standard (Figure 3.4). Moreover, many who work as specialists at cancer centres also work as generalists in units, this varies considerably between networks (SD7).

Radiotherapy

WE'RE A BIT SHORT OF EQUIPMENT - the number of people down at the hospital are queued up and they're going every day, all day long. If one machine breaks down, the whole lot falls back! (PATIENT, CEREDIGION)

3.18 Radiotherapy may be used to treat cancer (generally before or after surgery), but in some cases it is used as an alternative to surgery or to relieve the symptoms

of advanced disease¹¹. It is most often used for patients with breast cancer, followed by those with lung cancer. Before a patient receives radiotherapy, calculations must be made about the radiation dose and type, the area to be treated and the distribution of the dose. Treatment is prescribed by clinical oncologists, but others are involved in making the necessary calculations, maintaining the machines and giving the treatment (SD4).

3.19 Modern radiotherapy generally uses machines called linear accelerators (LinAcs), which deliver high energy x-rays and electrons to kill tumour cells. Radiotherapy equipment is expensive; one LinAc machine costs about £1m, not including the costs to house and maintain it. There is considerable inequality in the distribution of such equipment across England and Wales; the number of machines per million of the population varies from under two to six¹² (SD9). Altogether, there are about 160 machines in use, with another 30 on site but out of use for maintenance or other reasons. Much of this equipment is old and some is well past its recommended lifetime. These difficulties have now been recognised and a national plan has been developed to iron out inequalities and replace old equipment in England. Some lottery funding (New Opportunities Fund) has been allocated for this purpose. In Wales, there is a similar plan to replace equipment, with centrally allocated funding for this purpose.

3.20 As well as inequality in distribution, there is considerable variation in how intensively machines are used, and this affects both costs and waiting times. A recent survey shows that the number of patients treated per machine in each year varies from around 300 to nearly 1200¹³. This is because of: differences in the prescribing of radiotherapy (partly as a result of different patient needs), the way the machines are used, and the availability of staff. Attention is needed to all three (SD4).

3.21 First, despite widespread agreement on the total amount of radiotherapy needed under specific circumstances, consultants hold varying views about how it should be given. Some prescribe higher individual doses (fractions) over a shorter period and others prescribe lower doses over a longer one. Because the time taken on the machine on each occasion is not very different whatever the dosage, those hospitals which tend to prescribe over a longer period are reducing the number of patients any one machine can treat. The effect of these policies on the prognosis of patients, and on their experience of side-effects, in most cases remains unclear and more research is urgently needed. One trial is currently under way to assess the effect for breast cancer¹⁴. This information is explored in more detail in SP5 and SD4.

3.22 Second, there is also large variation in the use of machines. For instance, over two-thirds of all machines are used only between 9 a.m. and 5 p.m. on weekdays. Some hospitals/trusts have introduced extended working hours, using machines ten hours a day or more or on a Saturday (SD9).

3.23 Finally, some areas also have major problems in recruiting key staff. In the hospitals/trusts visited, there were serious problems recruiting therapeutic

There is considerable inequality in levels and consequent access to a range of specialist resources, including non surgical oncologists and radiotherapy equipment.

radiographers; three quarters had one or more vacancy and one had one third of its posts unfilled. The average trust vacancy rate for therapeutic radiography is 12%¹⁵. There seems to be surprisingly little relationship between the annual use of a machine and staffing levels (SD9). Clearly, if there are enough staff available, it makes sense for hospitals to extend their working hours.

3.24 Some of the patients we spoke to noted problems regarding travel to radiotherapy treatment. This is a particular problem where public transport is poor, distances to hospital are great and hospital transport arrangements limited. Communal transport, however, can mean a very long day, where all patients must wait for each other. Some hospitals provide hostels where patients who live far away can stay during treatment.

Coordinating the treatment programme

THERE'S NO CO-ORDINATION BETWEEN ONE AND THE OTHER. I've seen several consultants and on various occasions they've sent me for blood tests. I've said "Where's the result of my last blood test?...Where's the co-ordination between the pathology and the consultant and the records?"
(PATIENT, WALSALL)

3.25 Increasingly complex treatment programmes require even better coordination. This includes formal arrangements for professionals working together and the use of guidelines to ensure standard practice wherever possible.

Multidisciplinary teams

THE FIRST ONE TO SAY "CANCER" WAS THE ONCOLOGIST. The surgeon said "it's nasty, you've got to have chemotherapy", all that sort of thing, but he never said the word "cancer".
(PATIENT, WALSALL)

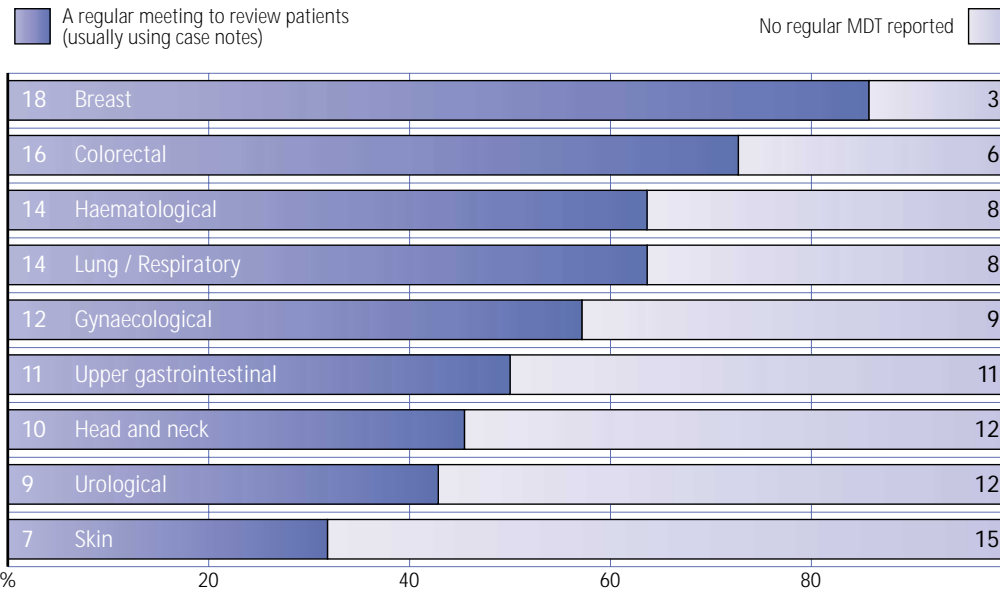
3.26 A major recommendation of the Calman-Hine Report was the widespread establishment of multidisciplinary teams (MDTs) to address patient needs from diagnosis onwards (SD5). These teams are intended to provide good coordination and communication between those providing treatment and care as well as pooling expertise. Teams existed in some areas prior to the Calman-Hine Report. Although MDTs are increasingly common, there is still considerable progress to be made in the case of some types of common cancer (Figure 3.5). In a few areas, MDTs meet to reflect on cancer care generally, rather than to discuss the specific needs of individual patients.

Figure 3.5

Trusts/hospitals that report multidisciplinary teams that meet regularly

Although MDTs are increasingly the norm, there is still considerable progress to be made in the case of some types of common cancer

By type of cancer



Trusts/hospitals are included if they offer a service that includes diagnosis and planning therapy. A different number of trusts provided information for each type of cancer. The numbers on each bar are the actual number of responses. The bars have been drawn to a percentage scale to allow for comparisons

Source: CHI/AC site visits to 22 trusts/hospitals in England and Wales (2000/01)

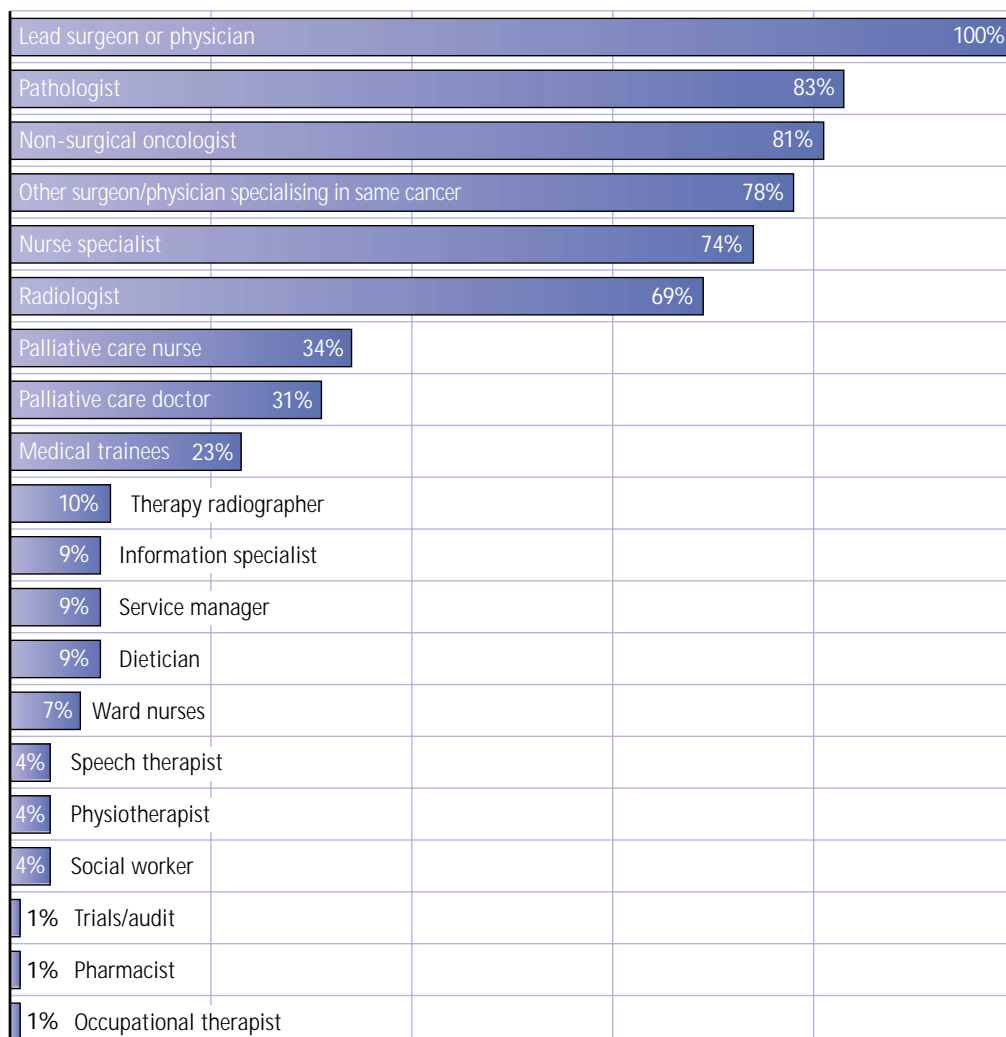
3.27 Where they do exist, MDTs usually include the lead surgeon or physician, other doctors and specialist nurses, as recommended by COG Guidance (Figure 3.6). Those involved consider that such teams are a good use of their time, helping them to learn what each of them is doing and so plan good patient centred care. They also help new patients to obtain access to specialists in chemotherapy and radiotherapy. When the teams discuss patients' needs throughout treatment, they are a useful way of checking that individual specialists follow accepted guidelines. At a minimum, they make sure that individual consultants are not working in isolation. Although there is no research evidence on their cost effectiveness, it has been suggested that MDTs might result in savings by reducing the length of hospital stays or the need for readmission. One study of women with ovarian cancer has shown, however, that being cared for by an MDT also improves outcomes¹⁶.

3.28 But a number of problems were reported to arise in practice. Although most teams meet on a weekly basis, in some areas and for some types of cancer, they meet only monthly or less (SD5). Some specialists, such as pathologists and radiologists, work with several different types of cancer, making the time commitment especially difficult. This problem is compounded because it tends to affect those specialties whose consultants are already in short supply. There are also time and travel problems for specialists who work at several locations. Because it is difficult to schedule MDT meetings, they are often held outside normal working hours or in

Figure 3.6

Membership of patient-planning MDTs, for all cancer types

Where they do exist, MDTs usually include the lead surgeon or physician, other doctors and specialist nurses



Note: Membership does not necessarily mean that these people attend all meetings

Source: CHI/AC visits to 21 trusts/hospitals (113 MDTs) in England and Wales (2000/01)

lunch hours (SD5). In some areas, what passes for an MDT is neither multidisciplinary nor a team.

3.29 In order to use time and resources well, the functions, membership and timing of these MDTs may need to change depending on the type of cancer and local circumstances. Attendance by some specialists, such as pathologists and radiologists, might sensibly be limited either to certain parts of a meeting or to those meetings centred on diagnosis. Attention is also needed to making these teams work more effectively. All trusts should provide administrative support so that paper records can be made of decisions (currently such recording is done to a variable extent in patients' notes) (SD5). If team members are not in the same area, a tele-medicine link with consultants should be considered, as has been set up in Bronglais Hospital in

Wales. There is a need for clear lines of accountability, including who is responsible for leading the team. Time may need to be spent on group dynamics, including training in working as a team.

3.30 However useful MDTs can be for ensuring good coordination between specialists, some problems are likely to remain. Communication problems with others outside the team need to be dealt with, for example with GPs and district nurses, together with patients' wider needs for support. There is a clear need to make sure that patients who do not have an MDT receive good care, and coordination must be maintained on other fronts, for example, to make sure that records are full and accurate where patients attend more than one hospital.

Despite considerable growth in multidisciplinary team working to plan and coordinate treatment, it has yet to be instituted in many hospitals and for many cancers.

Clinical guidelines and standards

43

DEPENDING WHAT TYPE OF CANCER IT IS, you can't really avoid statistics about survival rates and things like that.' (PATIENT, CAMBRIDGESHIRE)

3.31 The Calman-Hine Report argued that there should be agreed local policies (or guidelines) about treatment for each of the major forms of cancer, to make sure that patients get the most up to date treatment and care. There should also be agreed standards, setting out goals for managing patient care, for example, how quickly patients should be seen. Our study found that, other than for lung and breast cancers, there were no agreed treatment policies in 50% or more of the trusts visited (Figure 3.7) (SD4). There are also differences depending on the type of treatment as policies are more common for surgery and radiotherapy than for chemotherapy. But where guidelines do exist, interviews with lead cancer doctors suggest they are based on evidence, often drawn from COG guidance¹⁷.

3.32 The real question, of course, is whether agreed guidelines are followed in practice. The lead consultants we interviewed generally felt that they were, but their views were rarely backed up by an audit. This needs to change. The Avon, Somerset and Wiltshire network has set up a system for regularly auditing standards and publishes the results, including the performance of named hospitals. In Wales, audit results have been published for several years. Most recently, this included information on the performance of individual hospitals (SD10).

As treatment processes become more complicated and the numbers of people involved increase, clear communication between professionals and with patients becomes increasingly necessary. This requires planning, organisation and support involving all staff.

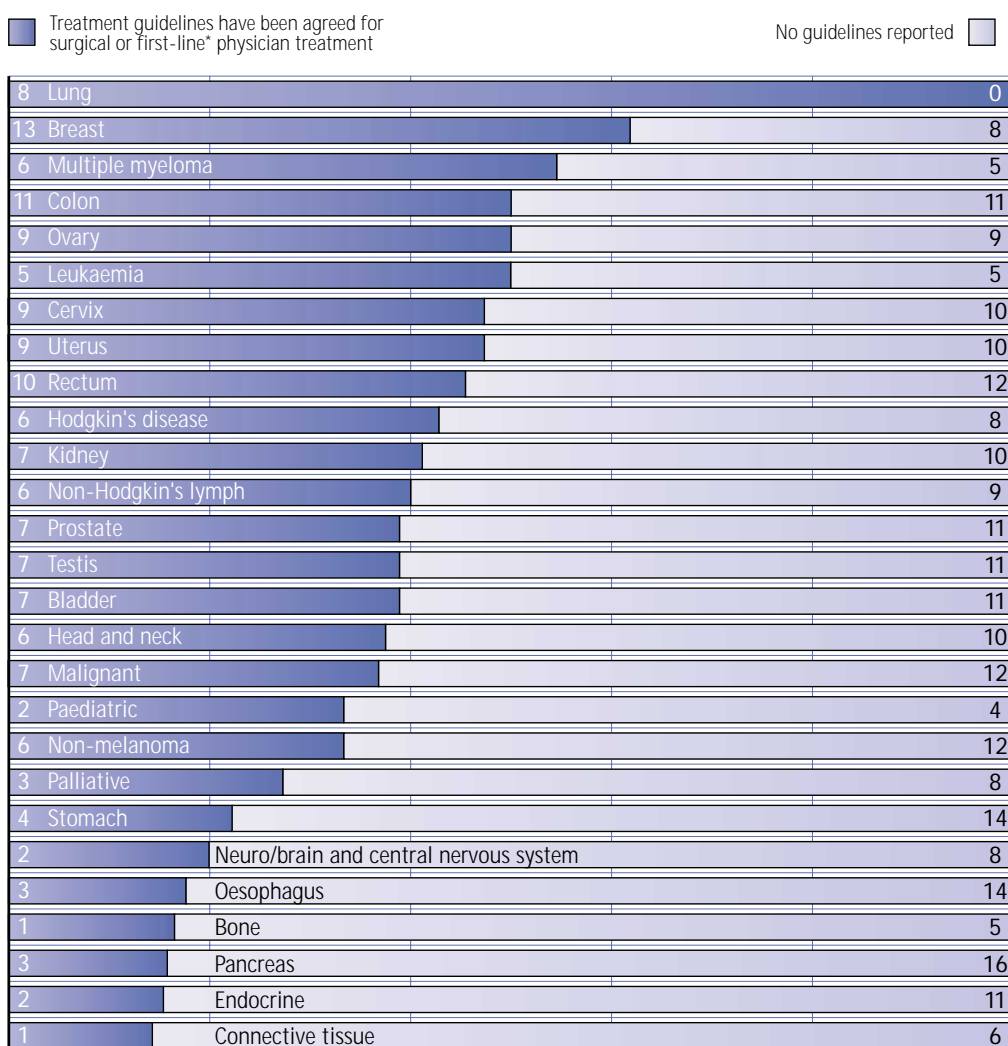
3.33 Patients are rarely consulted locally over the development of standards, although there is the occasional example where they are. The East Sussex, Brighton

and Hove Health Authority commissioned discussion groups with patients about their experiences to influence broad planning¹⁸. In the South West region, patient opinions were invited on standards for head and neck cancer. These opinions were then included in regional standards for practice and, later, national ones¹⁹. The same region has also continued to involve patient representatives in working groups for different forms of cancer. In Wales, patients are able to participate in standard setting as they are represented on the national Cancer Services Coordinating Group (CSCG); patients also sit on advisory cancer steering groups, wherever possible.

Figure 3.7

Trusts/hospitals with agreed treatment guidelines for various cancers

Other than for lung and breast cancers, there were no agreed treatment policies in more than half of the trusts visited



Notes: 'first-line' means the consultants' patients are usually referred to by GPs for assessment, diagnosis and initial management, for example, by a chest physician. A different number of trusts provided information for each type of cancer. The numbers on each bar are the actual number of responses. The bars have been drawn on a percentage scale to allow for comparisons

Source: CHI/AC site visits to 14 trusts and hospitals in England and Wales (2000/01)

3.34 The National Cancer Director has recently published national standards in England and has started a review process to assess networks against them, due to be completed soon²⁰. The results should be published locally so that patients and their organisations are aware of how well their services match up to the standards. In Wales, health authorities monitor how well trusts are performing against the minimum standards each year. The CSCG and its cancer steering group publish a report with a national overview of these findings²¹.

Involvement in clinical trials

I WAS IN HOSPITAL FOR A COUPLE OF WEEKS... They asked if I'd be willing to go on a trial and I agreed. I was so relieved that they could do something for me, because you assume the worst, I just wanted to give something back. (PATIENT, CAMBRIDGESHIRE)

45

3.35 At the moment only a small proportion of patients with cancer are involved in clinical trials. Our research suggests that cancer centres can be involved with 50 or 60 different trials, whereas smaller hospitals usually take part in only a handful (SD4). Many consultants outside centres argue that they are too pressed providing a basic service to be able to give time to trials. They also claim that trials need dedicated nursing and information support. Yet obtaining their involvement would help to alert them to the results of trials and therefore affect their future practice. It is also sometimes argued that patients in trials tend to receive better care. Of course, more involvement with trials would benefit the wider public as clinical trials are the best way of identifying better treatments.

3.36 The All Wales Cancer Trials Network was set up in 1997 to support those running clinical trials and to try to increase participation in them. The revised minimum standards now include a requirement for all patients, where appropriate, to be offered entry into a clinical trial. In England the new National Cancer Research Institute should improve the use of trials through better coordination.

Discharge and follow up

MY DISTRICT NURSES WEREN'T TOLD THAT I WAS COMING OUT OF HOSPITAL. I'd been out two or three weeks before... When they did get to know that I was out, they said "good Lord, what are you doing out of hospital for this length of time and we didn't know about it?" (PATIENT, DARLINGTON)

3.37 Many patients are discharged from hospital without difficulty, but problems can arise. Many patients discharged after cancer surgery will need supportive care

of one kind or another, so there must be great emphasis on good communication with the organisations likely to be involved. Yet patients are often discharged without careful planning (SD2). This was a very strong message from discussions with both GPs and district nurses. GPs said that they often do not know that a patient is out of hospital until the patient contacts them, so that district nurses have to arrange services and equipment at short notice. Both GPs and nurses felt that discharge letters often arrived too late and lacked important information about a patient's circumstances and prognosis.

3.38 Patients who are likely to need some help after discharge should receive an early visit from a discharge coordinator or district nurse to assess their specific needs for services or equipment at home. Our research suggests that this happens sometimes, but not always (SD2). Other agencies who may become involved, such as social services, also need to be told. The GP should receive full information within 24 hours of the patient's discharge. This information should cover: the patient's diagnosis, prognosis and treatment plan, the patient's immediate needs on discharge and what the patient has been told.

3.39 Follow up systems should: monitor any recurrence of cancer, handle new symptoms, such as fatigue or pain, and allay general anxiety among patients and their families. Side effects of radiotherapy may develop only after several months and patients can be unsure whether they are signs of recurrence of the cancer or simply a result of the treatment itself. Many hospital wards and day chemotherapy areas provide a follow up telephone number, which can be very reassuring for patients. Good systems need to be in place for all patients after treatment.

3.40 District nurses can be heavily involved in follow up, visiting patients to provide both practical care and emotional support. Some of the patients we spoke to welcomed their close involvement and concern. We found that many specialist nurses also make home visits at this point, particularly haematological and breast specialist nurses. Gynaecological and urological nurses were less likely to do so (SD8).

3.41 Medical follow up is normally the responsibility of the hospital specialist, but in some cases it is passed to the GP. Some people argue that the GP arrangement is more sensible as recurrences usually show up between consultant visits and it is easier for patients to get to their GP. Research with patients suggests a mixture of views. Some would prefer to see a specialist at this stage, while others are happy to see their GP, with some variation by type of cancer²². At the very least there should be some clarity between consultants and GPs about who is doing what and patients should know who to go to if they have concerns. Most of the cancer surgeons and non surgical oncologists we spoke to felt that follow up was well co-ordinated between themselves and GPs, but some GPs reported poor experiences here (SD9). In the final analysis, there is a need to balance patients' wishes with the resources involved, as oncologists carrying out this kind of work could otherwise be seeing new patients more quickly.

Supportive care

‘NEEDED TO TALK TO SOMEBODY WHO WASN’T INVOLVED, who I could open my heart out to. I spent most of the [counselling] sessions in floods of tears, but it certainly did a lot of good for me.’ (PATIENT, LANCASHIRE)

3.42 People who have cancer are not only concerned about treatment. They also have a deep need for good emotional support and social and spiritual care, and to be kept well informed throughout their illness. They also need advice about managing symptoms and side effects. These issues merge into palliative and terminal care. We discuss these in the next chapter.

3.43 The patients we spoke to were very positive about the caring nature of their consultants. There were many examples of doctors sitting on beds and talking to patients, explaining treatment and generally going out of their way to be helpful and reassuring. This included late night visits or telephone calls at weekends to check on progress. Examples of lack of consideration, impatience or the use of jargon were few and far between. Patients valued greatly a sense of humour among consultants.

3.44 Specialist nurses were also reported as particularly supportive, as they had a valued expertise in cancer combined with a willingness to spend time with patients. There was also considerable praise for other clinic nurses and those providing stoma care. Criticism of nurses tended to relate to a single incident or individual.

3.45 Some patients also praised the support of their GP or district nurses during their treatment, but others felt that they had been abandoned at this point. Many GPs told us of their regret that they had lost track of patients during this period, in some cases because they lacked information about the diagnosis or treatment plan. District nurses aim to introduce themselves to patients soon after diagnosis so that they can provide support as needed.

3.46 The formal psychology and counselling services available to patients with cancer are limited (SD2). Only about half the consultants interviewed thought that counselling was available to newly diagnosed patients by referring them to a qualified psychologist. Even where these services exist, there can be long waits. One area reported an eight month waiting list. Few of the patients we spoke to had been offered counselling. Yet even when counselling was offered, many were reluctant to accept it. Some patients suggested that formal emotional support should be offered to their partners as they had particular problems coping with the diagnosis.

3.47 Some patients had joined cancer support groups of various kinds and found these extremely helpful in coming to terms with their experience. These groups were also a source of very useful information. Other patients had talked extensively to people who had experience of cancer. In many cases these people were friends or acquaintances, but sometimes it developed through regular meetings on chemotherapy or other wards. Some people found emotional support through

discussions with voluntary organisations, such as CancerBacup. Those working closely with patients should provide information on both national organisations and local support groups.

Patient centred care

AT THE RADIOTHERAPY UNIT, THERE'S NOTICES EVERYWHERE "We know our radiographers are busy, but if you've got a problem, please stop them." It doesn't matter where you go, they're throwing their good nature – and everything they've got – to you. They just can't do enough'. (PATIENT, KENT)

48 3.48 Patients felt that they had received a high standard of both treatment and care from most of the health care professionals they had come into contact with. They had been shown great consideration by consultants and others, and an open and honest approach beyond what many of them had been expecting. They particularly welcomed the support of specialist cancer nurses who give them help both at the time of diagnosis and throughout the treatment process. Where one person, such as a consultant or specialist nurse, seemed to take responsibility for their care, this was especially valued.

3.49 There are problems, however. Some patients experience long delays before treatment begins. There is great variation in the extent to which specialists carry out surgery. Patients receiving radiotherapy can have very different regimes, affecting the amount they need to travel to and from home. More patients are receiving attention from multidisciplinary teams, and this should bring about better coordination and communication between specialists. But not all patients are covered by these teams. Few patients seem to be offered formal counselling, although this can help them to cope better. The whole process is fraught with uncertainty about what is going to happen and when.

3.50 There are also major communication problems before, during and after treatment. This is particularly the case between those working within hospitals and outside them. It is most obvious when patients are discharged after surgery and the equipment and services they need at home have not been organised.

3.51 There is also too little coordination for follow up, and problems throughout treatment, with many GPs effectively losing track of their patients at just the time when they should ideally know what is happening to them. These issues are not just about good administration. They also affect good patient care. Good care, poorly delivered, is always diminished.

Treatment and care:

Hallmarks of a good service and questions patients might ask

Hallmarks of a good service

- Hospitals tell patients how long they will have to wait for treatment. Treatment delays are monitored and reduced wherever possible
- Patients know what to expect with regard to their treatment
- Surgery is performed by a specialist or sub-specialist for those cancers where evidence shows that this improves the result.
- Chemotherapy is prescribed by a medical or clinical oncologist and its administration is supervised by a nurse with appropriate training.
- Chemotherapy is provided in local cancer units for patients' convenience.
- All treatment is carried out efficiently to delays for patients.
- All treatment (and care) plans are discussed by a multidisciplinary team, which includes cancer nurses and all the main consultants.
- If patients attend more than one hospital, their records are full and accurate in each.
- Good supportive care is available throughout treatment and patients know how to get help, including from sources outside the NHS

Questions patients might ask

- How quickly will the treatment start?
- What will the treatment be like and how long will it take? Will there be side effects and what can I do about them?
- Is my surgeon a sub-specialist in my form of cancer?
Is this important for my type of cancer?
- Is the doctor prescribing my chemotherapy a medical or clinical oncologist?
Will the nurses on hand during the chemotherapy have the right training?
- Can I have the chemotherapy in my local hospital?
- Can my surgery, radiotherapy or chemotherapy be speeded up by being carried out outside of normal office hours?
- Will my treatment be discussed by a multidisciplinary team?
Does this team include cancer nurses as well as doctors?
- Will all the hospitals I attend know about my diagnosis and treatment?
- Who should I contact if I am worried about my diagnosis, treatment or prognosis?
What help is available for my family?
What patient support groups are there in my area?

Hallmarks of a good service

- Detailed plans are drawn up to meet the needs of each patient at home after they have been discharged from hospital. The GP is told that the patient has been discharged.
- The responsibility for follow-up is clearly established for all patients
- All networks have agreed treatment guidelines and standards.
- Patients are consulted on the development of treatment guidelines and standards
- The use of treatment guidelines and standards is audited and the results are published.

Questions patients might ask

- Will I need special equipment or support when I get home? Will I get this?
Does my GP know I am being discharged?
- Who should I contact if I have questions or concerns, once my treatment has finished?
- What are the treatment guidelines and standards for my treatment and care?
Can I see them?
- Has anyone asked patients what they think of the guidelines?
- Do you audit the use of treatment guidelines and standards in this area?

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Palliative and terminal care

THERE WAS NOBODY THERE FOR MY FAMILY. I didn't see anyone after the hospital, when I came out. I had no support at all from any group. Nobody came to the house to ask how I was getting on, how I was coping'

(PATIENT, LANCASHIRE)

52

4.1 Once a patient's treatment has been completed, there are several different scenarios. Some patients will be disease free. Some of these will still need regular follow up, at varying intervals depending on the type of cancer, and may also receive

Once treatment has finished, patients can feel abandoned, unless there is appropriately planned handover to the community.

supportive care from time to time, for example from a specialist nurse. Others may find that they no longer need cancer services at all. But those who still have cancer will need palliative care to reduce pain or other symptoms and to provide emotional support. If the cancer is stable and not expected to progress quickly, the patient may only need this care occasionally. But if the cancer is incurable and progressing quickly, specialist palliative – and eventually terminal – care is essential.

4.2 The term palliative care is often used loosely to refer to the care of people who are in the process of dying, i.e. confusing palliative with terminal care. Indeed, some patients find the term distressing as they understand it to mean they will die soon. We use the term here to cover patient needs for care over an extended time. We use the term terminal care for the last few weeks of a person's life.

Palliative care

I'VE HAD SO MANY PEOPLE COMING TO SEE ME – I had a sister from the hospice, she comes to see me whenever she can and if I want her. There seems to be so much support I haven't needed to go to the GP' *(PATIENT, KENT)*

4.3 When considering palliative care, there are issues concerning who provides the care and at what point, as well as the particular problems accessing such care out of hours. The role of hospices also deserves some attention here.

Providing palliative care

THE DISTRICT NURSE SEEMED TO BE PERFECTLY SKILLED IN LISTENING... She knows when to be quiet or when to ask the question and how to ask it, rather than just administer the bandages.' (PATIENT, PETERBOROUGH)

4.4 Palliative care involves efforts to relieve the symptoms of a disease, such as pain, nausea or fatigue in the case of cancer (and any side effects after treatment) combined with emotional, social and spiritual support. It engages the efforts of many different specialist and generalist professionals in hospital and in the community.

4.5 In hospital, specialist palliative care consultants may advise others on relevant issues or they may work directly with patients. Our research found considerable variation in the number of sessions provided by these consultants, ranging from none in three trusts visited to ten or more sessions in five others (SD2). Many of these consultants have a joint appointment with their trust and the local hospice. Most of those interviewed said they also visited patients at home. Some hospitals have specially designated palliative care areas, although this was only a minority of those involved in our research. One study suggests that only about one quarter of patients with cancer in England gain access to a palliative care bed¹.

4.6 Specialist palliative care nurses also advise others and see some patients, including at home. But not all hospitals employ these specialist nurses and there are considerable variations in numbers among those that do. Only about half of the specialist nurses interviewed said they visited patients at home. Some palliative care nurses are employed by other organisations, such as community trusts (SD2).

4.7 In the community, generalists such as GPs and district nurses often become more involved in providing care at this stage. Although GPs see only a few new patients with cancer in any given week, they can have a large ongoing caseload. Each GP is likely to look after 30 to 40 patients with cancer each year and, among these, is likely to experience five or six deaths. GPs have an ongoing medical and supportive role and some of those we spoke to stressed the importance of keeping aware of these patients' needs. District nurses visit patients at home to attend to symptoms and provide emotional support to patients and their families. Other professionals, such as dieticians and occupational therapists, can also become more involved at this stage.

4.8 Organisations outside the health service also provide help at this time. Local hospices with specialist staff often provide both symptom control and emotional support for people staying in them as well as day centres for patients with cancer. Some hospices also provide respite care, so that patients can stay for a while to give their families a break. Hospices do not exist in every area, however. Local authority social services departments and charities (such as Marie Curie) provide access to a range of other services, including sitting services.

The large number of people involved in palliative care often lack co ordination and leadership.

4.9 In principle, palliative care should begin as soon as there is recognition that it might be needed. Our research suggests, however, that this is not always what patients want. Many of the patients we spoke to did not want to discuss palliative care and did not feel it was appropriate to do so after their initial diagnosis, as it implied that they were very ill. There is an obvious tension between the good intentions of health care professionals to start palliative care as early as possible and the concern this can cause for patients. A simple change of name from 'palliative care' to 'supportive care' nurses might help here. A new supportive care strategy is currently being developed to provide people with cancer obtain the right professional support and care, as well as the best treatment. This strategy should tackle the issue of what to call the care so that patients are encouraged to use the service.

4.10 Even when active treatment has finished, patient needs are not always recognised. Furthermore, it is not always clear who is responsible for making sure that help and support are available. Cancer networks should work with local health professionals to create an appropriate system for establishing this responsibility. The specific arrangements may well vary from one place to another. The period immediately after hospital discharge can be particularly difficult for some patients. Having had regular attention from their cancer specialist, they can suddenly find themselves without immediate access to advice and feel abandoned. Moreover, this is often precisely the time when patients become fully aware of the seriousness of the situation, and this in turn increases the need for emotional support. It is also a time of stress for families for the same reasons. It is essential that patients and their families know who to contact for information or support.

4.11 With so many different people involved, there can be problems coordinating palliative care. The district nurses we spoke to were concerned that sometimes it is not at all clear who is 'in charge'. They also felt that those visiting patients' homes could find themselves in each other's way, much to the annoyance of patients as well as themselves. Patients should know who to contact first if there is any doubt. The key people should then be kept fully informed of the patient's needs.

4.12 Approximately three quarters of the hospitals/trusts visited had multidisciplinary teams focused on palliative care, involving both specialist consultants and specialist nurses. However, neither GPs nor district nurses are involved with these teams, despite their key role in providing palliative care (SD5). Arrangements are needed to make sure that they are informed about key decisions taken. There may also be a need for training in palliative care for non specialist staff, such as district nurses. The National Cancer Plan commits funding for this purpose in England. In Wales, standards require specialist palliative care teams to be integrated with cancer services, with effective communication with other organisations.

4.13 The adequacy of palliative care is a difficult matter to assess. Most of the palliative care consultants and specialist palliative care nurses interviewed felt that they did not see all patients who might benefit from their services, partly because of constraints on their time and partly because patients were not always referred to them. On the other hand, they felt that those patients they did see got enough time (SD2). Similarly, some of the GPs and district nurses we spoke to felt that they could not do justice to patients' needs and some district nurses regretted the need to cut visits short because of pressures to see other patients.

Help Out of Hours

AT 3 O'CLOCK IN THE MORNING, I don't know whether I turned in bed and kinked the line or what...the red light was flashing and I thought what am I going to do now? I rang the ward... She just talked me through it. They've told me, any problems, I can ring them. "It doesn't matter what it is - if you worry about anything, you ring us." (PATIENT, CEREDIGION)

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4.14 Palliative care services to cover patients' needs outside working hours are very patchy. The availability of specialist medical palliative care and specialist nurses is highly variable and serious concerns were expressed on this issue. Hospices and hospital wards may have a contact telephone number. Some hospital wards are readily accessible to former patients, although this is not always the case, and these wards may not anyway be the best place for patients to receive care at this stage.

4.15 All GPs have to provide out of hours arrangements The GPs we spoke to felt that these arrangements work reasonably well. However, there was some concern that patients could be admitted to hospital as an emergency without good reason because the doctor was not fully aware of their circumstances. A few areas have set up systems to provide key medical information to out of hours doctors, on computer or on paper. Patient held records are sometimes helpful, although they are not always brought up to date by everyone who has contact with the patient.

4.16 The availability of medication out of hours is a serious concern for both GPs and nurses. There are different views about whether strong painkillers should be left in the patient's house overnight in case of need. GPs' kits can sometimes run out during an evening. Some nurses learn which chemists keep stocks of key medications, so they can get hold of them out of hours. In an emergency, the GP or nurse may be able to get a pharmacy to open out of hours, especially at the weekend.

4.17 The availability of district nurses out of hours varies greatly from one area to another. We found that some areas offered district nurse services at any hour of the day or night, whereas others had no cover at all after 10 pm. Those working overnight often felt very pressured by the sheer size of the demand. Similar limits

Services for people needing palliative care are often in short supply, particularly out of normal working hours.

in out of hours provision were found in a study of district nurses carried out three years ago. One third of all trusts then provided no district nursing overnight, including on-call and, again, those who did were not always able to meet all requests for help². Arrangements for a 24 hour district nursing service are essential to help patients and their families cope with serious worries at this point. Networks should examine their policies and give priority to this need. A system has been set up in Wearside for terminally ill patients, with district nurses trained in palliative care available out of hours so that patients can stay at home. These nurses work closely with the specialist palliative care hospice team (SD2).

4.18 Some trusts provide a rapid response team to assess need and then provide 24 hour care. These teams are mainly there to avoid patients having to go into hospital. However, there may be limits to the number of patients who can be served at any one time and to how long any one patient can receive this care. These arrangements also vary in the extent to which they involve close working between district nurses and others such as social workers.

4.19 The Department of Health and Macmillan Cancer Relief, a major health charity, have recently looked into ways of improving out of hours care services³. They have called for better planning and improved medical and nursing cover out of hours. They are also concerned about access to drugs, the need for better communication with day time staff and better access to advice.

The role of hospices

I DON'T KNOW HOW I WAS REFERRED TO THE HOSPICE IN THE FIRST PLACE, but I remember thinking well, I'd give it a try, see what it was like. But sometimes you speak to people and they think oh, you go in there to die – it's not like that at all, not at all! (PATIENT, LANCASHIRE)

4.20 There has been a striking growth in the number of hospices over the past 20 years. In 1980 there were roughly 50 inpatient units, but today there are just over 200 hospice and palliative care units for adults in the UK, with nearly 3000 beds⁴. The number of hospices remains very uneven from one area to another, however. There are, for example, nearly twice as many hospice beds per million of the population in the best provided for region, compared to the worst. (Figure 4.1) Only about half of all health authorities surveyed in one study felt that hospice services in their area were reasonable⁵ (SD2).

4.21 There are also great differences in what hospices offer patients. Hospices are commonly viewed as providers of terminal care for patients with cancer. But in fact they offer a great range of services to patients and their families. Many have day centres which offer recreational activities, information, counselling and different forms of treatment, such as chiropody and complementary therapies.

Figure 4.1

Hospice beds per million population

Hospice beds are very unevenly distributed across England and Wales; there are nearly twice as many hospice beds

South east	65
North west	58
London	56
North & Yorkshire	51
South West	49
Wales	44
West Midlands	43
East	38
Trent	36

Source: *The Hospice Information Service. St Christopher's Hospice*

4.22 There are currently over 240 day care services, either independent or attached to hospice units, twice the number in 1990⁶. Again, there are considerable differences in the number of places available from one region to another. Some also offer respite care to give families a break from their caring responsibilities. About one third have out reach arrangements so that patients can be cared for by hospice staff at home⁷ (SP 2).

4.23 The patients we spoke to were mostly unaware of the wider services which hospices provide seeing them simply as the place to go when they were ready to die. A few, however, had used hospice services and spoke highly of them. Some patients can be unwilling to go into a hospice as they believe it is a sign that they are soon to die. In fact, about half of all people admitted to hospices are later discharged. Of nearly 60,000 admissions in a year, only 30,000 people die in a hospice in the UK⁸.

4.24 Funding for hospices has changed over time. In late 1989, the Government allocated £8 million for health authorities in England (for 1990-91) to enable them to increase their support for hospices and similar organisations. The intention was to move to matched (50%) funding on a national basis, although not for individual hospices. This commitment changed in 1993 and was withdrawn in 1996. The National Cancer Plan for England in 2000 acknowledged the inequality in hospice provision and committed an £50 million each year for specialist palliative care by 2004. Nonetheless, palliative care in hospices and hospitals is heavily funded by charitable donations. The NHS currently manages only one quarter of all adult hospices and palliative care units⁹.

Terminal care

The GP's very good. He calls in, if he's passing my house, to see how I am. And if I need him, he's there instantly. Now whether he does that for all of his terminally ill patients, I don't know, but I suspect he does. He's that sort of doctor! (PATIENT, PETERBOROUGH)

4.25 Palliative care tends to merge subtly into terminal care. While no one can be certain when death will happen, certain symptoms may show that it is likely. If the patient is at home, everyone involved (especially the GP and district nurse) tends to take on a more active role. District nurses told us that they sometimes return three or more times a day to families who need their help. GPs also said that they visited more often. Some even gave patients their home or mobile telephone numbers at this time.

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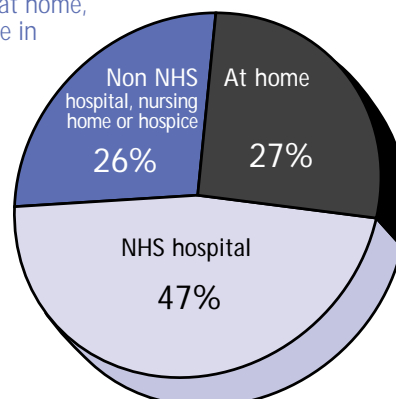
4.26 The needs of relatives are particularly important at this point. Terminal care can be an important way of helping relatives to cope with their experience and may ease their loss. They may need to learn about specific medication, for example to control pain, but more importantly, they often need a lot of emotional support. They can find it very distressing to see the person they care for deteriorating in front of their eyes. In some families, important issues may not have been resolved, leading to particular tensions.

4.27 Most people would prefer to die at home if possible¹⁰. Yet only one quarter of patients with cancer do so. Half die in hospital and the rest in non NHS care, including hospices and nursing homes (Figure 4.2). The decision to move the patient from home may be made positively, for example, because the patient will benefit from being in some other place. But it may also be the result of difficulties at home. This may be the lack of specialist equipment, such as a hospital mattress or bed, or relatives may find themselves unable to cope with the complex physical and emotional burdens imposed by caring for a dying person. It is essential that networks audit the equipment provided and take steps to make up for shortages.

Figure 4.2

Where cancer patients die

One quarter of patients with cancer die at home, half die in hospital and the remainder die in non-NHS care including hospices & nursing homes



Source: Data from Higginson et al (1998)¹¹

4.28 Because of uneven provision, access to a place in a hospice seems to vary enormously from one area to another. Some GPs told us that they had major problems in getting a hospice bed for a patient in need, but others said they rarely experienced difficulties. Access was said to be particularly difficult for an emergency at a weekend. Not being able to get a place in a hospice can be a major disappointment for patients who have come to know the people there through visits for day or respite care.

Too many patients are still dying in hospital against their own and their families' wishes.

4.29 Hospital care is also very uneven for dying patients. Some of the GPs we spoke to were concerned that patients could end up on acute care wards where they would be 'over treated'. And interviews with palliative care consultants and nurses confirmed this. When asked how terminally ill patients tended to be admitted to their hospital, they said that the most common route was through an admissions ward and then to a medical ward. Very few said that patients were admitted directly to palliative care beds, although some said that they would be admitted directly to the cancer ward where they had previously been treated (SD2). Some patients were also admitted to local community hospitals. GPs welcomed these hospitals, arguing that they were often more convenient for relatives.

4.30 Local arrangements for caring for terminally ill patients are likely to make a difference to what happens in practice. The Measham Medical Unit in Derbyshire has made a specific commitment to these patients. It involves multidisciplinary meetings within primary care to discuss the patient's needs. These meetings involve district nurses, social services, occupational therapists and others, as well as the GP. The unit has also set up a database of cancer patients so that it can audit the care provided. The percentage of terminally ill patients cared for at home has increased since the unit introduced this approach (SD2).

4.31 The National Cancer Plan for England has drawn attention to geographical inequalities in the availability of inpatient beds, home nurses and day places for palliative and terminal care patients. It commits funding to solve this problem.

Bereavement care

RIGHT THE WAY THROUGH, THERE WAS GOOD COMMUNICATION between the GP, the district nurse, the vicar and the Macmillan nurse.... They kept their beady eyes on me and came back at weekly periods after my wife died. "Just calling in, I've only got time for a quick cup of tea, how are you coping?" and the rest of it. That was marvellous.' (WIDOWED HUSBAND, BRISTOL)

4.32 The role of the NHS in cancer care does not stop when a patient dies. Some GPs and district nurses we spoke to said that they try to provide bereavement care to distressed relatives. This was mainly to help families come to terms with their loss.

But it could also be important to the professionals involved: GPs because of their ongoing relationship with the bereaved person and district nurses because they had developed a close relationship with the patient. Specialist palliative care teams may also help here.

4.33 Many GPs told us that they try to offer one appointment to a bereaved person, with either the GP or district nurse. This may involve visiting the person's home to give them enough time and attention. Both GPs and nurses were aware of a need to be sensitive to those who do not want this help. Sometimes, a whole practice was briefed when a patient was dying or had died so as to be sensitive to the needs of the patient's family.

Patient centred care

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THERE WAS SOMEONE IN OUR WARD – the family were around her bedside in hearing of everybody – who was told that they were making arrangements for her to go home to die. She didn't sleep all night and then the nurses were wondering why she was in the state she was.' (PATIENT, PLYMOUTH)

4.34 There is evidence of a profound commitment to palliative and terminal care among both doctors and nurses. And the extra effort they make for dying patients and their relatives is impressive. They visit more often, sometimes in their own time, and care deeply about making the experience of dying as dignified and comfortable as possible. Many also seem very sensitive to the needs of families at this time.

4.35 However, the service as a whole is not patient centred in the broader meaning of the term. There is great variation in access to specialist palliative care services, both in hospital and in the community. Those working with patients in their home clearly make every effort to do their best, but they are very stretched. There is a clear lack of coordination between all those involved in providing palliative and terminal care. The provision of care outside normal working hours is not consistent and generally not enough. Respite care, sometimes vitally important at this stage, is also not easily obtained. And there do not seem to be enough hospices, so that many patients who would ideally choose this option cannot do so.

Palliative and terminal care: Hallmarks of a good service and questions patients might ask

Hallmarks of a good service

- Someone takes responsibility for making sure that patients' needs for palliative care are recognised
- Specialist staff and premises are available for palliative care
Will I be able to talk to a palliative care consultant or a specialist palliative care nurse?
- Good arrangements are in place for palliative care outside normal office hours and patients are told about these arrangements
- Ongoing care of patients is co-ordinated and it is clear who is in charge
- Patients and their families have good practical and emotional support whenever they need it.
- Patients are able to die where they and their relatives choose, with good support for terminal care
- Someone takes responsibility for offering bereavement care.

Questions patients might ask

- Who will take responsibility for identifying any new needs for care, such as pain or tiredness?
Will someone also offer me and my family support?
- Will I be able to talk to a palliative care consultant or a specialist palliative care nurse?
- What do I do if I need help overnight or at a weekend?
- Who do I go to first if I need help or have questions?
- Who else can I talk to about how I am feeling?
What support is available for my immediate family?
- Will I be able to die where I want?
- After I die, who will offer my family support?

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The organisation of cancer services

EVERY INDIVIDUAL THAT YOU DEAL WITH, other than one or two exceptions, are kind and caring people, doing their best within the environment they're working in. They treat you with respect and try and help you. But, to me, the whole system doesn't work.' (PATIENT, PETERBOROUGH)

5.1 The previous chapters which focused on patients' experiences in obtaining a diagnosis, treatment and subsequent care, have shown considerable lack of co-ordination across the many organisations involved, and very different levels of service. These problems are partly because the large numbers of different people and complicated organisations involved in cancer care lead to both structural and operational difficulties. Separate organisations, with their own budgets and management structures, do not easily unite to serve a common local purpose. Moreover, despite a natural concern to do their best for the patient in front of them, hard pressed professionals can easily forget that patient centred care also requires keeping others informed. It is for precisely these reasons that the Calman-Hine report called for major organisational changes. This chapter deals with these changes.

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Introducing cancer networks

FROM WHAT YOU READ IN THE PAPERS, you've got this bureaucratic non medical layer of people, who are just business people at the end of the day.... Whether they are doing a good job or not, I don't know.' (PATIENT, BIRMINGHAM)

5.2 The Calman-Hine report called for the creation of a completely new kind of structure, to be known as a cancer network, covering the commissioning and delivery of all cancer services in one geographical area. The aim is to achieve more coordinated planning as well as common treatment standards for all patients in that area. In all, 34 cancer networks have been or will soon be formally established across England and three in Wales (SD10).

5.3 Networks are complicated partnerships of all organisations and professionals involved in commissioning, planning and providing cancer services in an area. They tend to cover a large geographic area and many organisations, including health

The central government initiative in setting up networks and assessing cancer centres and units against standards is welcome. These initiatives, if successful, will reduce variations in access and service provision.

authorities, hospital trusts, and primary care trusts and local health groups in Wales. To give one example, one network consists of eight provider trusts, 20 primary care groups, three primary care trusts and six health authorities. To add a further complication, some health authorities belong to more than one network. This makes for very complicated planning arrangements among the very different and traditionally independent organisations. And the difficulties are further increased by the separate financial and management accountability of these NHS organisations.

5.4 In all the areas visited, network boundaries and catchment populations had been set, although some referral patterns were still under discussion (SD10). There was also considerable evidence of close cooperation between the clinicians working within networks. In many networks, they have joined together into working groups for particular types of cancers, such as lung or breast, and are developing common standards and guidelines. In Wales, this is being done on a national basis. These relationships have also been helped in some areas by involving clinicians from more than one hospital in multidisciplinary teams.

5.5 Most networks have also appointed a set of cancer leads comprising of a lead doctor, lead nurse and lead manager (SD10). Some areas have also developed or are planning a network directory which lists these leads and the members of local multidisciplinary teams. This kind of activity should be encouraged. It should prove helpful in improving communication between everyone involved, as well as providing useful information for patients. Supporting clinicians to work together may indeed be one of the most effective ways of driving the broader network agenda forward.

5.6 The Department of Health and Macmillan Cancer Relief have recently made joint funding available so that every primary care group and trust (PCG/PCT) can have a cancer lead to facilitate involvement in cancer networks and improve support to patients. This lead may be a GP or a nurse. Recent research suggests that these posts are already developing. Three quarters of PCGs and PCTs surveyed in 2000 had identified someone with responsibility for developing cancer services¹. Primary care leads also have an increasing number of representatives on network management boards.

5.7 On the managerial front, however, networks have made less progress. Although network management boards have been set up in English networks, management relationships continue to operate along more traditional lines. Few of these boards include community representatives (SD10). In Wales, networks were still in the process of setting up management boards at the time of our visits. Networks were fully established by the end of October 2001².

5.8 Only one of the networks visited (Avon, Somerset and Wiltshire) seemed to be working as a truly joint enterprise, although there may be others not visited. It set up a management board early on, involving chief executives (or director level representatives) from both health authorities and trusts and employed a network manager. It made an active effort to involve the public in network decisions, including the publication of strategy statements. It also developed common standards for each of the main types of cancer and, for the most common, audited and published the results (SD10).

5.9 A major difficulty for cancer networks is the limited history among the organisations involved of working together towards a common goal. For example, there has been little joint commissioning between health authorities (other than for specialist services, such as bone marrow transplants), which might have served to develop a sense of unity (SD10). In England, regional offices have traditionally reviewed acute trusts separately, with little sharing of the results, so that no common overview about standards or other issues developed across them. Also, at the time of our visits, the recently set up network boards had little involvement from health authority and trust chief executives (SD10). This has made it more difficult for the boards to influence major planning decisions.

5.10 The non functioning of networks is not only to do with management. There are also major difficulties at the level of providing clinical services. For example, many patients are being referred by GPs in one network to specialists in another, because of referral patterns in the past and ignorance about the existence of networks (SD10).

5.11 The Calman-Hine report was not specific about how networks should be created. Each of the health regions in England, as well as Wales, was given responsibility for setting them up and each went about this task in a different way. Some took a directive, centralist approach, whereas others allowed networks to develop from the ground up. The result is great variation in the structure and functions of the networks. From those visited, it seems that most real progress in networking has been achieved where local professionals have developed networks themselves. There has been less success with a more directive approach. For example, one more directive network had not yet got senior managers involved and had little sharing of standards across the network. Well-thought through processes for setting up networks are of course helpful to ensure subsequent progress, but they are not enough to make progress on their own. Other factors are also important.

5.12 At the time of the Calman-Hine report's publication (1995), the concept of a local cancer network was highly radical, requiring both managerial and clinical

Developing systems to achieve closer working between clinicians and managers at network level is particularly challenging because of:

- the complicated pattern of organisations and people involved
- the limited amount of joint working between hospitals and between professionals within primary and secondary care

relationships to develop across hospitals and other organisations, rather than solely within them. This can be described as a shift from a 'vertical' approach (where relationships are within a single organisation) to a 'horizontal' one (where relationships are with people in other organisations). It is not surprising that there have been difficulties in making such a change work in practice.

5.13 The paragraphs above suggest that progress in setting up networks has been slow and uneven. At the time of our visits, many seemed to be organisations on paper only and few were yet operating as planned. But it is also the case that central guidance had only recently been issued. Networks are now more clear about what is expected in terms of both structure and aims, and they also have some funding for management. Chief executives and primary care lead clinicians will now be involved. But the task ahead will not be easy. There will be a need to work much more closely with GPs because of the greater role of primary care trusts and local health groups in commissioning services, and patients must also be involved more closely in network planning (SD10).

The designation of cancer centres and units

WHEN I SAW THE DOCTOR, HE SAID "I'll talk to so and so because you'll get it done quicker... ." He might say that to everyone. It frightens me when you listen to other people...there's no system to the whole procedure.' (PATIENT, PETERBOROUGH)

5.14 The Calman-Hine report not only recommended creating new cancer networks. It also argued that there should be two types of facility, cancer centres and units, designated to provide cancer services. This was to make sure that patients could obtain treatment as close to their homes as possible, while developing some centres of specialisation and excellence. Cancer units, usually in district general hospitals, would provide basic cancer services to their local population. Cancer centres would also provide basic services to their local population, but in addition would provide more specialist services, including radiotherapy and the more complicated forms of inpatient chemotherapy and sophisticated diagnostic techniques. These centres might comprise of more than one hospital. As with networks, differentiation of centres and units is not yet working as fully as intended, although some progress has been made here³ (SD10).

5.15 Again, as with networks, the process of designating which existing hospitals should become centres and units was not at all straightforward. The criteria and the assessment process varied from one region to another. These decisions were often politically, professionally and – for the institutions - financially fraught, as they would inevitably affect patient referrals, the amount and kinds of activity carried out for patients and the number of clinical posts for any one hospital, as well as the clinical practice of individual doctors. These factors widely affect the finances and services of the hospitals involved.

5.16 Our study took place in the midst of a great deal of activity around this process. In most English regions, centres have now been fully designated, but some cancer units are still in the process of being assigned (SD10). More importantly, day to day working arrangements (for example; communication, appointment systems and shared protocols) have rarely been fully worked out. In Wales, the Cameron Report identified three cancer centres and their referring cancer units.

5.17 Some useful developments have taken place, however. Almost all trusts have now appointed a lead clinician (not necessarily a doctor) to further develop and co-ordinate cancer services, as proposed by the Calman-Hine report. (Please note these are separate from the lead doctors set up at network level. In some trusts, lead doctors have been appointed for particular types of cancer, most commonly colorectal and breast cancer and usually the designated sub specialist for that type of cancer. Most trusts have also appointed lead cancer nurses, although their involvement can vary in practice from only one session per week to a full time position. Most trusts have also identified a lead manager for cancer services. Very occasionally, other staff groups, such as pharmacists or dieticians, have appointed a cancer lead (SD10).

5.18 At the same time, much progress has been made within centres and units to develop closer working between professionals in the interest of patient care. As described in chapters 2 and 3, there is more specialisation among nurses and consultants, and more multidisciplinary teams have been established. There is still a long way to go before all patients benefit from these developments and a great deal of inequity across cancer types has been identified.

5.19 One area of particular concern is the poor availability of information. Although the trusts and other organisations we approached tried hard to meet our requests for information about their services, what they provided was often poor or incomplete. This explains some gaps in the information provided throughout this review. But much more worryingly, it suggests that the organisations responsible for cancer services (and the clinicians working within them) are not in a position to routinely account for those services. Nor can they give patients information such as how long they can expect to wait between different stages of treatment, whether there is local specialisation, or whether they are using equipment as efficiently as possible. It is impossible for any cancer centre, unit or network to know how well it is doing on delivering care to patients without such key information. Not only are data systems poor but they do not allow information about different parts of the overall process to be connected.

5.20 There is an urgent need to improve information systems. Before making this kind of major investment, however, local managers and clinicians will need to agree

Information about local services is lacking, suggesting that those responsible cannot routinely account for them nor tell patients how long they may need to wait, whether specialisation exists or whether equipment is being used as efficiently as possible.

what they are trying to achieve for patients and what measures might help to identify the extent to which they are doing so. It will then be important to set targets and measure performance against them. Even doing this for a sample of patients, using paper based systems would be a good start. In both England and Wales there is a commitment to implementing new information strategies for cancer services⁴.

5.21 There was little patient involvement in the changes made to centres and units in England. Only one in six authorities consulted patients specifically about the designation process, although roughly one third consulted their community health council (CHC), which is intended to represent patients, but its brief goes well beyond cancer⁵.

Looking to the future

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ANYONE WHO COMPARES THE NHS TO THE THIRD WORLD simply has never seen the third world.' (PATIENT, LONDON)

5.22 A number of issues arise for the future. These concern both the organisation of cancer services within individual hospitals and broader network planning, including networks' possible commissioning role.

5.23 At the level of individual consultants and others working closely with patients, hospitals and trusts must provide more help to bring about the necessary changes. Cancer leads, for example, have no formal powers to challenge other clinicians. Their influence depends on gaining the respect of their colleagues. If any real improvements are to be made to patient care, they will need to be developed as clinical leaders and given the authority to make sure that protocols and standards are followed. Decisions will also need to be taken regarding who will drive forward improvements for those cancers where there is no lead clinician. In the case of multidisciplinary teams, there is a need for administrative support to help them, and specified time for those involved (SD5).

5.24 None of this will be easy. The Cancer Services Collaborative in England provides a good example of the constant effort needed to turn around a whole system of care. Its projects are heavily supported by project managers, who produce the information necessary for consultants and others to create baseline measures on their own performance, set targets and monitor progress over time on their achievement.

There is a lack of clarity over the authority of the networks and the accountability of other organisations to them.

Everyone involved receives training in improvement techniques. The difficulty of the task is fully recognised and there is much focused external support from the Modernisation Agency (an organisation set up to help trusts and health authorities improve NHS services). With the decision to extend this work from the nine projects to the whole of England, it will be a tall order to replicate this everywhere.

5.25 Because of the complicated patterns of services needed to support patients throughout their illness, comprehensive networks for cancer services are essential. But great effort will be needed to set up clear lines of accountability and develop managerial and other relationships to support them. This is crucial both at the level of formal decision taking and for creating informal working partnerships. Attention will need to be given both to the barriers to professional change and to creating effective incentives. Many key organisations will need to be involved, such as primary care trusts and local health groups (PCTs/LHGs) with their growing involvement in commissioning services. Good working relations will also be needed with others outside the health service, such as local hospices. The ways of actively involving these and others who provide cancer care have not yet been made clear.

5.26 Those within each network will also need to work closely together to develop a common investment and planning strategy. Difficult decisions will be necessary as some services developed in local areas are likely to be at the expense of others. This cuts across traditional planning systems and will need considerable clinical and management skill and influence. To take one example, directors of finance from many different organisations must manage competing priorities and will not find it easy to prioritise the needs of patients with cancer over the needs of those with other conditions. But they will need to work together if networks are to function as a coherent whole. Network management will involve taking some unpopular decisions, affecting both professional jobs and public views about the location of services.

5.27 Leadership at network level will be necessary for a range of planning and monitoring issues. So, for example, networks will need to pay attention to managing the whole workforce rather than individual organisations thinking about their own staffing. The same will be true of equipment requirements. Audit of activity and general quality of care will be needed across the whole system, not in isolated parts or organisations, and patients will need to be consulted at network level in planning cancer services and in monitoring the services currently provided.

5.28 The broader role of networks needs to be made clear, particularly whether they are to commission services. If so, the question arises of how much influence they can have without budgetary control. Giving networks a cancer budget would involve a fundamental shift. Most health care resources, such as staff and equipment, are used by patients with a wide range of conditions. It is very difficult to work out which resources should be assigned to a single condition (or group of conditions such as cancer), as this involves making many assumptions and even some arbitrary decisions. In fact, this kind of system has rarely been attempted and most planning simply specifies levels of general resources (SD10). It may be that recent work on health resource groups may help here. Information must improve a great deal so that accurate plans and budgets can be implemented across networks.

5.29 The Cancer Plan announced the intention to set up some initial pilots in England involving new approaches to commissioning cancer services. In February

2001, English cancer networks were invited to submit proposals to pilot new approaches, with a particular focus on ways of assessing commissioning strategies against clear criteria. These will involve networks considering how best to use cancer care resources throughout a patient's illness. It is expected that they will also involve combining PCGs/PCTs' knowledge of their populations with the expertise of local cancer care providers. The pilots may focus on a single area of care, such as chemotherapy, or may take a whole system approach.

5.30 We write at a time when the National Health Service is on the edge of further change. In both England and Wales, a layer of management is due to be removed. In England, health authorities will be abolished, along with regional offices, and 28 strategic health authorities (SHAs) will be created. In Wales, health authorities will also be abolished. PCTs will take responsibility for commissioning in England and LHG will become local health boards (LHBs) in Wales.

5.31 On the one hand, these changes bode well for developing cancer networks, as their populations are roughly the same as those in SHAs and the same boundaries are, in theory, possible in England. Indeed, it will be essential for SHAs to be actively involved in making networks work. On the other hand, the amount of organisational change involved, on top of the great changes already taking place, will put heavy pressures on everyone involved, and will lead to great personal uncertainty about professional futures. There will also be a steep learning curve among the commissioning services within PCTs and LHBs, for whom cancer services will be only one of many concerns. The task should not be underestimated.

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Reflections on progress in cancer services

6.1 Most of the people who organise and provide cancer services agree that the Calman-Hine Report marked a key moment. It promoted the development of good practice as seen at that time in some services for patients with breast cancer, including team working across organisational and professional boundaries and more specialisation in one type of cancer by both doctors and nurses. And, very importantly, it brought cancer to the top of the health agenda.

6.2 Since the report was published, the NHS has made important improvements in cancer services. These include:

- speeding up the process of bringing patients into the cancer system, with most urgently referred patients now waiting less than two weeks from GP referral to the first hospital appointment
- creating more arrangements for hospital tests and clinic appointments to be scheduled together, so reducing the need for patients to travel to hospital on several occasions
- expanding multidisciplinary working, with clinicians joining together both to plan individual patients' care and to develop good practice guidelines that benefit all patients
- improving the sensitivity with which consultants discuss the diagnosis and prognosis with patients
- developing outreach services by doctors specialising in chemotherapy and radiotherapy, so that patients can receive treatment closer to home
- creating plans to address existing inequalities in staffing and equipment
- establishing standards across the whole of Wales and within some English regions, so that everyone involved with patients knows what to aim for

6.3 Yet six years later, we find that these improvements have not been made everywhere. As set out in Annex 1, progress in implementing many of the key recommendations of the Cancer Report has been slow. The Government has

recognised this in the Cancer Plan for England. Similarly, the National Assembly for Wales has sought to make sure that the key recommendations for the cancer agenda are in place through the NHS plan for Wales. From the patient's point of view, the main problems remaining are:

- Often care is not 'joined up' because of a combination of poor communication and a failure to plan care systematically across everyone involved. All medical and other professionals treating or providing care for a patient should understand their own role in relation to that of others and should then make sure that the care plan, taken as a whole, deals with all of the patient's needs. For example, hospital staff do not always tell GPs about a patient's diagnosis or treatment plans quickly (or even at all). Moreover, there can be confusion between the diagnosing surgeon, oncologists, nurses and primary care staff about who should be assessing whether patients having chemotherapy or radiotherapy can cope at home and, if not, making sure that help is provided. The result is that patients can be left unsupported and can find it difficult to manage their daily lives.
- Many patients do not have access to someone, such as a specialist nurse (CNS), who both knows about their cancer and has the time to listen to their concerns and explain the system to them. Patients who have access to such a person value their help highly, especially as they understand that medical consultants, however kind they are individually, do not have enough time.
- There are few ways for patients to express their concerns throughout the process either individually or as a group.

6.4 At the same time, there are a number of underlying failures within the wider cancer system:

- Some patients do not receive the treatment which scientific study has shown is best for them. It is not satisfactory that the treatment and care received can sometimes depend purely on the particular doctors and others involved. We found examples of considerable variation at all stages of diagnosis, treatment and care, ranging from the criteria GPs use to refer patients, through the diagnostic tests used, to the type of surgery, chemotherapy and radiotherapy offered.
- The system also allows the quality of service to vary with different types of cancer. Every cancer patient should experience reasonably short and anxiety free waits, be well informed and psychologically supported, have chemotherapy and radiotherapy prescriptions based on evidence, be offered help if needed with daily living and be provided relief from symptoms and side effects. Although many patients with breast cancer do receive this kind of service, fewer patients with other types of cancer do so. This may be because of the nature of the illness in some cases - more complicated tests take longer to arrange and interpret, for example, but all patients should have a multidisciplinary approach to managing their care, a specialist surgeon, specialist nurse support and good written information.
- In some hospitals, machinery that is both very expensive and in short supply is not used efficiently, there are variable day surgery rates and lengths of stay for

inpatients undergoing the same procedures and varied patterns of follow up in outpatients. Where there is inefficiency, patients will suffer. It can mean that they wait longer for tests or treatment or that they lack important support because money that might have funded a specialist nurse has been wasted.

- At present, networks have only been fully developed as managed organisations in a handful of places, despite being a recommendation of the Calman-Hine Report. And too few patients and non hospital staff are involved in managing them. Most network boards tend to involve only health authority and acute hospital representatives. This distorts the provision of services, exacerbating communications between primary and secondary services and making it difficult to hear the concerns of patients.

6.5 Commendably, the new Cancer Plan in England, and the plans for cancer services in the NHS Plan for Wales, are quickening the pace of change. They reinforce the gains described at the start of this chapter and aim to spread them further. They set targets for improving waiting times and aim to reduce other inequalities in access to services. They are also committed to addressing staff and equipment inequalities and boosting network development.

6.6 But formal plans can only change how services are organised and arrange for equipment and staff to deliver them. They cannot make sure that services are provided in a truly patient centred way and they should not be expected to do so. To resolve the problems listed requires a change in the attitudes and behaviour of everyone working with patients and in the way the wider cancer system is managed.

6.7 The following are the priorities for attention over and above what is set out in the formal plans:

- Those working closely with patients should try to look at the service from the point of view of the individual patient. This will make the important relationships between all those involved with treatment and care more obvious. For example, new patients should feel confident that their GP will know all about their treatment plan or, following treatment they should feel that their district nurse is aware of their needs when they leave hospital. Some patients may have more complicated requirements, possibly involving others outside the NHS. Frail 75 year olds living on their own may need someone to make sure that they can cope with daily living when they are starting a debilitating course of chemotherapy. These issues involve a change of mindset, but targets may also help here (for example, the GP should be told of a diagnosis within 24 hours). Involving patient organisations in planning will help to make their opinions count.
- Those managing services should give equal attention to all cancers. The needs of patients with different types of cancer have not been dealt with in the same way, with different efforts having been made to improve services for different types of cancer. Services for patients with cancers such as stomach, pancreas and prostate must be brought up to the standard of those for patients with breast cancer.

- Those managing cancer services should concentrate on finding ways of making sure that clinicians provide what their peers in other sub specialties have. This may mean investing in more specialist nurses; organising more multidisciplinary team meetings, further surgical sub specialisation, developing new guidelines and carrying out open audits to assess practice against guidelines.
- Those managing cancer services should resolve network issues. The Government and the National Assembly for Wales can set the direction of change, but better leadership is needed at local level. We have seen excellent examples of local staff translating the words of the Calman-Hine Report into specific local action for the benefit of patients. But far too often, there is an expectation that someone else will take the initiative. Local staff need to join together and seek improvements, resolving professional and managerial differences with NHS and other organisations. Particular attention is needed to make sure that lead clinicians have the authority to take a truly leading role. Other organisations, such as hospices and primary care groups and trusts, must be represented on network boards.

6.8 A number of questions about the role of networks remain for the Government and the National Assembly for Wales:

- i. Who must the networks answer to?
- ii. What levers are there in individual networks to make sure that the changes needed happen?
- iii. Will network commissioning and providing functions be separated?
- iv. Will NHS finance arrangements be fundamentally changed so that networks can hold separate budgets for acute cancer care and add to those the community share that is currently separate for cancer?
- v. If so, what happens to budgets for patients with other types of disease?
- vi. And how will the new strategic health authorities and primary care trusts/local health boards, affect everyone's ability to maintain and improve services for patients with cancer?

Answers will need to be found soon in order to continue building on the progress experienced to date.

6.9 Many of the individual people visited across the cancer services are working hard to provide an excellent service to patients. Our criticisms do not apply everywhere. Indeed, most of the improvements we have suggested can be found in one place or another. This simply leads to the clear question of why they cannot then be replicated elsewhere.

ANNEX 1

Summary of evidence on the implementation of the Calman-Hine Report

Note: Our remit was to review progress in the implementation of the Calman-Hine Report. Developments regarding individual recommendations are noted in each chapter and are summarised in table form to provide a broad picture of progress as a whole. Overall, progress has been slow in implementing many of the key recommendations, but the pace of change has now quickened.

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Progress with Calman-Hine principles and recommendations

Progress has been slow in implementing many of the key recommendations in the Cancer Report, but the pace of change has now quickened

Key (chapters and supporting papers give detailed data):

*	**	***
Few patients yet receive these benefits	Some patients receive these benefits	Most patients receive these benefits

<i>Calman-Hine principles and recommendations#</i>	<i>Ref##</i>	<i>Key findings from our study</i>	<i>How many benefit?</i>
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Obtaining a diagnosis and discussing the treatment options:

Appropriate GP referral patterns	6.iv	National guidelines issued, variably used by GPs.	**
		Central referral offices in hospitals reduce delays in providing outpatient appointments.	***
		In some types of cancer, many non-urgent referrals are found to have cancer; in only a few places are non-urgent referrals seen quickly	*
Site specific outpatient consultation	4.2.2	Increasingly the case for most cancers	***
Clear information and assistance about options and outcomes	3.1.iii	Some hospitals provide written information tailored to local situations; most common for breast cancer patients and least common for upper GI (of the common cancers)	**

<i>Calman-Hine principles and recommendations#</i>	<i>Ref##</i>	<i>Key findings from our study</i>	<i>How many benefit?</i>
		Mastectomy/breast conserving surgery ratio varies to a degree that suggests clinicians may over influence choice assistance about options	**
Good communication between staff and patients	3.1.iv	Many patients praised the attitude of doctors, nurses and other cancer staff Some doctors, and more cancer nurse specialists (CNSs), have received training in how to break bad news	*** *
Access to cancer site-specific clinical nurse specialists (CNSs)	4.2.16	Varies by cancer – best for breast cancer, least available (of the common cancers) for gynaecological and upper GI cancer patients	**
Ward and outpatient care planned/led by nurses with cancer education	4.2.16	Many cancer CNSs and chemotherapy nurses have cancer qualifications Very few surgical or medical ward nurses do so	** *
Treatment and care:			
Surgical sub specialisation essential	4.2.3	Most trusts have agreed lists of sub specialists In practice, many patients are treated by surgeons and physicians who are not agreed sub-specialists and do not treat many cancer patients each year	*** *
Units to have volume of work sufficient to maintain sub-specialisation	4.2.3	Most closely defined and followed for breast cancer. Most networks have yet to resolve where gynaecological services should be provided.	**
Professional bodies to research and publish minimum volume standards rapidly	4.2.5f 5.7	In a few cases, but the evidence base is still small	*
Chemotherapy: specialised locations and staff	4.2.19	Most chemotherapy is prescribed by non surgical oncologists, and administered by specialist staff	***
Minimum 5 non-surgical oncology sessions in units	4.2.11	About half of units meet this standard	**
Minimum 8 non-surgical oncologists in centres	4.3.4	Perhaps fewer than half of centres meet this standard [incomplete data]	**
Multidisciplinary consultation & management essential	4.2.11	Varies by cancer and area of the country	**
Urgently develop guidance on managing common cancers	6.vi	Expert group guidance on five types of cancer published between 1995 and 2000; pace and completeness therefore not 'urgent'	**

<i>Calman-Hine principles and recommendations#</i>	<i>Ref##</i>	<i>Key findings from our study</i>	<i>How many benefit?</i>
Agreed protocols across network	4.1.4 4.2.8f	Fewer than 50% of trusts report agreed surgical, chemotherapy or radiotherapy guidelines across all types of cancer	**
Monitor treatment and outcomes; Audit to monitor development of the service network	3.1.vii 4.2.3 5.8	Occurrence of audit within individual trusts varies by cancer and place Openly published audit results, comparing hospitals across a network are very rare	** *
Psychological aspects to be considered	3.1.vi	About half of lead consultants say they have access to a trained psychologist by referral	**
Palliative and terminal care:			
Specialist palliative care services in cancer units	6.xi 4.2.1 7	Palliative care specialist doctors, nurses and beds vary greatly within acute hospitals	**
Specialist palliative care in the community	6.xi 4.5.2	Specialist palliative community nurses, hospices and night services at home vary widely	**
Coordinated follow up between centre, units and GPs	6.iv	More than half of hospital lead consultants and non surgical oncologists believe that follow-up is coordinated between themselves and GPs	**
The organisation of cancer services:			
Take account of users' views	3.1.iv	Half of HAs report some involvement of patients and/or the CHC in planning, but interviews and documents suggest their role is limited	*
Good communication between sectors	3.1.v	No systematic audit; focus group GPs report problems (eg, see next entry)	**
Information should reach primary care on day of discharge	4.6.8	Little audit data available; focus group GPs report problems with both timeliness and content of discharge letters	*
Cancer centres and units should be established	6.iii, 4.1.1, 4.7.4	Most centres have been designated Unit designation partially completed	*** **
Develop integrated networks	6.iii, 4.1.1	Most networks' catchment populations and organisational membership are identified and agreed Few networks have developed functioning management, and few contain GPs or community representation	*** *
Develop primary care team management of cancer	6.vii, 4.1.2	Little attention so far paid: e.g., no nationally agreed primary care standards, minority of networks have GPs on boards	*

<i>Calman-Hine principles and recommendations#</i>	<i>Ref##</i>	<i>Key findings from our study</i>	<i>How many benefit?</i>
Unit lead clinicians with specific sessions	6.v, 4.2.8	Most have identified leads; a majority of trust lead doctors have a sessional allowance, and a minority of trust lead nurses have specifically-designated time	**
Participation in trials	4.2.10 6.xii	A minority of trusts are involved in available trials	*
Manpower and education discussions with appropriate professional bodies	6.ix 6.xii	Yes	***
Contracting for specific improvements in service	4.7.1	Specific chemotherapy and radiotherapy contracts/service agreements common	***
Separate contracting for cancer surgical services	4.7.2	Some include quality standards (e.g., two-week wait); costed agreements are rare	*
General:			
Uniformly high quality of care	3.1.i 6.i	Collating across many indicators, the best progress has occurred for breast cancer patients, but progress is much slower for gynaecological, prostate and upper GI patients (of the common cancers)	**
Close to patient's home	3.1.i 4.1.1	Most local hospitals provide outpatient assessment and testing for the common cancers Some progress on non surgical oncology outreach	*** **
Patient-centred services	3.1.iv	Key examples: <ul style="list-style-type: none"> ■ waiting times for urgent outpatient appointments are mostly good ■ waiting times are often much longer for tests and treatment ■ some trusts offer pre-booking of appointments 	*** * **

#Excludes issues not within our remit – e.g., screening, prevention, registries, paediatrics and other very specialised services, or very detailed/specific recommendations

Calman-Hine paragraph number

ANNEX 2

Milestones in cancer policy 1995-2001

England

- 1995 Publication of the Calman-Hine Report
Establishment of the Cancer Guidance programme
- 1997 Publication of *The New NHS* white paper (waiting times policy)
£10m per annum dedicated funding for breast cancer
- 1998 £10m per annum dedicated funding for colorectal cancer
- 1999 £10m per annum dedicated funding for lung cancer
Two week wait policy introduced for breast cancer
Downing Street summit on cancer
Cancer identified as a 'top' priority, with appointment of minister responsible for all aspects of cancer
Appointment of National Cancer Director
Establishment of Cancer Services Collaborative
- 2000 Publication of referral guidelines for patients with suspected cancer (for GPs)
Rollout of two week wait policy to other cancers
Publication of the NHS Cancer Plan
- 2001 Publication of manual of cancer services standards
Peer review appraisals of all secondary and tertiary cancer service providers, using published standards
Action plan for cancer registries
Primary care lead clinician initiative announced
Endoscopy training pilots announced
Education and support for district and community nurses in the principles and practice of palliative care initiative

Wales

- 1995 Publication of the Calman-Hine Report
- 1996 Publication of the Cameron Report, setting out plans for the implementation of the Calman-Hine Report in Wales
Cancer Programme Office set up
- 1997 Establishment of the Cancer Services Coordinating Group, to oversee the implementation of the Cameron Report
All Wales Cancer Steering Groups established for nine cancers and specialist palliative care
All Wales Cancer Trials Network set up
- 1997-99 Publication of minimum standards for nine common cancers and specialist palliative care
- 1999-2001 Compliance of multidisciplinary teams to minimum standards monitored
National snapshot surveys of waiting times for initial consultation and treatment
Retrospective national audits of some cancers commissioned
- 2000 Publication of revised All Wales minimum standards
Publication of Cancer Information Framework
- 2001 Publication of *Improving Health in Wales*, a plan for the NHS including attention to cancer and including a specific requirement for trusts to meet the minimum
Standards by the end of 2001

NOTE

Guidance on individual cancers have been published as follows:

- 1996 Improving Outcomes in Breast Cancer
1997 Improving Outcomes in Colorectal Cancer
1998 Improving Outcomes in Lung Cancer
1999 Improving Outcomes in Gynaecological Cancer
2001 Improving Outcomes in Upper Gastrointestinal Cancer
2002-05 Others in planning

ANNEX 3

A note on supporting papers and data

As noted in the text, this short report is complemented by five supporting papers as well as considerable detailed supporting data. Both are available on the Commission for Health Improvement and Audit Commission web sites [www.chi.nhs.uk and www.audit-commission.gov.uk] and the first three supporting papers are also published separately.

Supporting papers

- SP1 Farrell, Christine. *There's No System to the Whole Procedure: Listening to Patient Views and Experiences of Cancer Services*. CHI/AC 2001.
- SP2 Farrell, Christine. *Patients' Views and Experiences of NHS Cancer Services: A Review of the Literature*. CHI/AC 2001.
- SP3 Richardson, Ann. *Cancer and Primary Care: The Views and Experiences of General Practitioners and Community Nurses in Caring for People with Cancer*. CHI/AC 2001.
- SP4 CHI/Audit Commission, *Methods Employed for the Cancer Review*. CHI/AC 2001.
- SP5 Richardson, Ann. *The Role of GPs and Community Nurses in Cancer Care: A Review of the Literature on their Activities and Perspective*. CHI/AC 2001.

Supporting data

- | | |
|--|--|
| <p>SD1 Who Gets Cancer and their Survival</p> <p>Incidence</p> <p>Survival</p> <p>Age</p> <p>Deprivation</p> <p>Geographical differences within England</p> <p>European comparisons</p> | <p>Patient-friendly arrangements</p> <p>Services to promote the quality of life</p> |
| <p>SD2 Services with a Human Face</p> <p>Communicating with patients</p> <p>Waiting times</p> | <p>SD3 Primary Care</p> <p>Role</p> <p>Diagnosis and referral</p> <p>Not all patients begin their pathway via GP referral</p> |

SD4 Varied Clinical Practice

- Guidelines
- Audit
- Trials
- Diagnosis
- Chemotherapy
- Radiotherapy

SD5 Multidisciplinary Team Working (MDT)

- Multidisciplinary team working defined
- Is the concept well-accepted by doctors?
- Patient-planning MDTs
- Joint clinics

SD6 Sub-Specialisation

- Sub-specialisation: the issue
- Is the concept of sub specialisation accepted and established?
- Surgeons and physicians
- Pathologists and radiologists

SD7 Non-surgical Oncologists

- Numbers
- Out-reach
- Sub specialisation
- Balancing out reach and sub specialisation

SD8 Cancer Nurses

- Cancer nurses
- The number of clinical nurse specialists (CNSs)
- Qualifications
- CNS role
- CNS management

SD9 Resources and Efficiency

- Costs
- Staff
- Diagnostic and radiotherapy equipment
- Bed use
- Follow up

SD10 Planning, Development and Organisation

- Over arching issues
- Planning and commissioning
- Network development
- Trust management

ANNEX 4

Organisations visited as study sites

As part of our research we carried out site visits to a sample of networks in England and Wales. The purpose of these visits was to collect detailed information on how cancer services are organised and delivered in England and Wales. We also visited two networks during the development stage of our research. Further detail on the methods used in our study are available in the supporting paper *Methods Employed for the Cancer Review* (SP4).

NORTHERN & YORKSHIRE REGION

NHS Executive Northern & Yorkshire Regional Office
 South Tees Community Health Council
 North Yorkshire Health Authority
 Tees Health Authority
 Cancer Care Alliance of Teeside, South Durham and North Yorkshire
 North Tees Primary Care Group
 South Tees Acute Hospitals NHS Trust
 South Durham Healthcare NHS Trust
 Northallerton Health Services NHS Trust
 Tees and North East Yorkshire NHS Trust
 St. Theresa's Hospice

NORTH WEST REGION

NHS Executive North West Regional Office
 North West Lancashire Health Authority
 Fylde Primary Care Group
 Preston Acute Hospitals NHS Trust
 Chorley and South Ribble NHS Trust
 Morecombe Bay Hospitals NHS Trust
 Guild Community Health Care NHS Trust

TRENT REGION

NHS Executive Trent Regional Office
 Nottingham Community Health Council
 Nottingham Health Authority
 Mid Trent Cancer Network
 Broxtowe and Hucknall Primary Care Group
 Nottingham City Hospital NHS Trust
 Queen's Medical Centre Nottingham University Hospital NHS Trust
 The Kings Mill Centre for Health Care Services NHS Trust
 Nottingham Community Health NHS Trust

WEST MIDLANDS REGION

NHS Executive West Midlands Regional Office
 South Birmingham and East Birmingham Community Health Council
 Walsall Health Authority
 Birmingham Health Authority
 Walsall East Primary Care Group
 University Hospital Birmingham NHS Trust
 The City Hospital NHS Trust
 Walsall Hospitals NHS Trust
 Birmingham Specialist Community Health NHS Trust
 John Taylor Hospice

EASTERN REGION

NHS Executive Eastern Regional Office
 Cambridge Community Health Council
 Suffolk Health Authority
 Cambridgeshire Health Authority
 West Anglia Cancer Network
 West Suffolk Borders Primary Care Group
 Addenbrooke's NHS Trust
 Papworth Hospital NHS Trust
 Hinchingsbrooke Health Care NHS Trust
 Peterborough Hospitals NHS Trust
 Lifespan Healthcare NHS Trust
 St. Nicholas Hospice

WALES

National Assembly for Wales
 Iechyd Morgannwg Health Authority
 Neath and Port Talbot Local Health Group
 Swansea NHS Trust
 Carmarthenshire NHS Trust
 Ceredigion and Mid-Wales NHS Trust
 Pembrokeshire and Derwen NHS Trust

LONDON REGION

NHS Executive London Regional Office
Camden Community Health Council
Enfield and Haringey Health Authority
Camden and Islington Health Authority
North London Cancer Network
West Haringey Primary Care Group
Royal Free Hampstead NHS Trust
University College London Hospitals NHS Trust
Whittington Hospital NHS Trust
Barnet and Chase Farm Hospitals NHS Trust
North Middlesex Hospital NHS Trust
Camden and Islington Community Health Services NHS Trust
North London Hospice

SOUTH EAST REGION

NHS Executive South East Regional Office
Canterbury and Thanet Community Health Council
East Kent Health Authority
West Kent Health Authority
Kent Cancer Network
Channel Primary Care Group
Maidstone and Tunbridge Wells NHS Trust
East Kent Hospitals NHS Trust
East Kent Community NHS Trust
Pilgrims Hospice, Canterbury

SOUTH WEST REGION

NHS Executive South West Regional Office
Cornwall and Isles of Scilly Health Authority
South and West Devon Health Authority
South and West Devon Cancer Network
North Cornwall Primary Care Group
Plymouth Hospitals NHS Trust
Royal Cornwall Hospitals Trust
Plymouth Community Services NHS Trust
St Luke's Hospice, Plymouth

Development sites

We visited two networks during the development of the site-visit tools:

SOUTH WEST REGION

NHS Executive South West Regional Office
Bristol & District Community Health Council
Avon Health Authority
Avon, Somerset and Wiltshire Cancer Services
North Bristol NHS Trust
Taunton & Somerset NHS Trust
United Bristol Healthcare NHS Trust
Bath & West Community NHS Trust
General Practice (Dr Stephen Illingworth, Bristol)
St Peter's Hospice

WEST MIDLANDS

NHS Executive West Midlands Regional Office
Coventry Community Health Council
Coventry Health Authority
Nuneaton & Bedworth Primary Care Group
George Eliot Hospital NHS Trust
North Warwickshire NHS Trust
Mary Ann Evans Hospice
Walsgrave Hospitals NHS Trust

Glossary

Audit

A method by which those involved in providing services assess the quality of care. Results of a process or intervention are assessed, compared with a pre-existing standard, changed where necessary, and then reassessed.

Barium enema

Technique for examination of the bowel. Barium sulphate, introduced into the bowel through the anus, is used to coat the inner surface of the colon and rectum so that it can be seen using x-rays.

Biopsy

Removal of a sample of tissue or cells from the body to assist in diagnosis of a disease.

Calman-Hine Report

The name commonly used for the major report on cancer in England and Wales, published in 1995, giving rise to many recent changes in the organisation of cancer services. It was prepared by a Committee, chaired by Dr Kenneth Calman (then, Chief Medical Officer, England) and Dr Dierdre Hine (then, Chief Medical Officer, Wales)

Cameron Report

The name commonly used for the major report on cancer in Wales, published in 1996. The report focused on implementation of change in the organisation of cancer services. It was prepared by a committee chaired by Professor Ian Cameron, then Provost and Vice Chancellor of the University of Wales College of Medicine

Cancer network

A new structure for bringing together the organisations and people who commission and provide services in the field of cancer to deliver a comprehensive cancer service for an area covering a population of about one to two million people.

Chemotherapy

The use of drugs that kill cancer cells, or prevent or slow their growth.

Clinical Nurse Specialist

A nurse who specialises in the care of patients with cancer, often working with patients with a particular type of cancer (like breast cancer or colorectal cancer) from the point of diagnosis or with patients with palliative care needs.

Clinical Oncologist

A doctor who specialises in the treatment of cancer patients, particularly through the use of radiotherapy, but who may also use chemotherapy.

Combined clinic

A clinic for patients where they will meet all (or most) of the clinicians likely to be involved in their care and possibly some others, such as specialist nurses

Course

The total treatment episode of chemotherapy or radiotherapy for one patient, often spread over a number of weeks or months and usually made up of a series of visits, e.g. on consecutive weekdays, once a week or once a month.

CT

Computed tomography. An x-ray imaging technique.

Endoscopy

Examination of the interior of the body using an endoscope, a tubular device with a light at the end, inserted through the anus, through an incision in the abdomen or down the oesophagus to the stomach or beyond.

Fraction

Radiotherapy is usually given over several weeks. The dose delivered each day is known as a fraction, as it is part of the total dosage.

Linear accelerator (LinAc)

A radiotherapy treatment machine which targets high energy radiation beams precisely at a tumour. Newer machines allow beams to match tumour shape.

Local health groups

In Wales only. These groups bring together family doctors, community nurses and others involved in health care. They contribute to local health improvement programmes and have a budget reflecting their population's share of the available resources for hospital and community health services, general medical services and prescribing.

Medical Oncologist

A doctor who specialises in the treatment of cancer by chemotherapy.

MRI

Magnetic resonance imaging. A technique used to produce images to enable investigation of organs of the body. Does not require the use of x-rays.

Multidisciplinary team

A group of doctors and others concerned with the treatment and care of patients with a particular type of cancer, who meet regularly to discuss patient treatment and care

National Cancer Plan

Published by the DoH in 2000. Sets out national standards for cancer services in England.

Oncologist

A doctor who specialises in treating cancer. See Clinical & Medical Oncologist above.

Palliative

Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it. Hence palliative care, palliative chemotherapy.

Primary care group

Groups of GPs, nurses and other health professionals working together to improve the health of local people, develop primary and community services and to contract secondary care. Primary care groups are formally constituted subcommittees of the health authority.

Primary care trust

Primary care trusts are evolving from primary care groups. They have the same functions as primary care groups but will also commission some secondary health care services for their population and directly provide some community health services.

Protocol

A policy or strategy which defines appropriate action.

Randomised controlled trial (RCT)

A type of experiment used to compare the effectiveness of different treatments. The crucial feature of this form of trial is that patients are assigned at random to groups which receive the interventions being assessed or control treatments. RCTs offer the most reliable (i.e. least biased) form of evidence on effectiveness.

Radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill tumour cells.

Remission

A period when cancer has responded to treatment and there are no signs of tumour or tumour related symptoms.

Specialist

A clinician most able to progress a patient's diagnosis and treatment or to refer a patient when appropriate.

Taxane

A type of drug used to treat cancer. Examples include docetaxel and paclitaxel

Ultrasound

High frequency sound waves used to create images of structures and organs within the body.

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