

**A POLICY FRAMEWORK FOR COMMISSIONING  
CANCER SERVICES**

*A REPORT BY THE EXPERT ADVISORY GROUP ON CANCER  
TO THE CHIEF MEDICAL OFFICERS OF  
ENGLAND AND WALES*

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**GUIDANCE FOR PURCHASERS AND PROVIDERS OF CANCER  
SERVICES**

**APRIL 1995**

## CONTENTS

	PAGE
1. BACKGROUND	2
2. INTRODUCTION	4
3. GENERAL PRINCIPLES	6
4. RECOMMENDATIONS	7
4.1 THE NEW STRUCTURE FOR CANCER SERVICES	7
4.2 THE CANCER UNIT	9
4.3 THE CANCER CENTRE	15
4.4 CHILDREN AND ADOLESCENTS WITH CANCER	19
4.5 PALLIATIVE CARE	20
4.6 THE RELATIONSHIP OF CANCER SERVICES WITH PRIMARY CARE	22
4.7 THE DEVELOPMENT OF THE PURCHASING PROCESS	24
5. IMPLEMENTING THESE RECOMMENDATIONS	26
6. SUMMARY OF RECOMMENDATIONS AND ACTION POINTS	29
7. BIBLIOGRAPHY TO MAIN REPORT	32
 MEMBERSHIP OF THE EXPERT ADVISORY GROUP	 ANNEX A
 HOSPITAL BASED CANCER SERVICES THE RELEVANCE OF SPECIALISED CARE	 ANNEX B

## 1. **BACKGROUND**

1.1 Cancer places a heavy burden of disease on the community. One in three people will get the disease and one in four will die from it. Its multiple sites, presentations and complications and the complexity of its treatment present a major challenge to the NHS. In addition, the individual consequences of the diagnosis of a malignant disease for patients are far reaching and profound. Cancer is still regarded by the public as an especially threatening disease and one which to some extent is still a taboo subject.

1.2 The Health of the Nation White Paper identified the potential for reducing deaths from cancer by prevention and screening, and the Service has shown its commitment to realising that potential. Many health carers are especially concerned with the early clinical diagnosis of cancer and its management at first presentation, usually by surgery. Subsequent treatments may be time-consuming and unpleasant for patients and not always effective. If cancer is advanced at presentation or recurs after initial therapy the outcome is often poor and the burden of palliative care upon the health care system is substantial.

1.3 There are huge economic consequences resulting from cancer. The cost of cancer care to the NHS is estimated to be as much as 6% (over £1 billion) of NHS hospital expenditure but the effects on the economy go far beyond this to include substantial financial burdens upon families and carers resulting from the disabilities and deaths of people during their productive middle years.

1.4 Cancer is not a single disease but a range of diseases with some common features but also distinct characteristics that vary according to anatomical site and morphology. A few common cancers cause a large part of the pressure on patients, their carers and the health services. Cancers of the lung and lower bowel in both sexes, breast in women, and prostate in men, between them make up around half the total number of cancers registered in the UK (excluding non-melanoma skin cancers).

1.5 Research in cancer covers a wide spectrum including basic biomedical sciences, applied laboratory research, epidemiology, clinical research and treatment development and health services research, including the evaluation of symptom control and palliative care.

1.6 The Expert Advisory Group on Cancer noted with concern that in the UK there were apparent variations in recorded outcomes of treatment. The difficulties of ensuring that the populations studied and the methods of data registration within

the country and between countries were acknowledged and the need for further studies was evident. The Group recognised the key role of cancer registries.

1.7 The overall incidence of cancer is rising. It is predominantly a disease of the elderly. With an ageing population some increase is to be expected, but there are some cancer sites, notably breast, prostate and skin where the recorded incidence is rising faster than can be accounted for by this alone.

1.8 It was against this background that the Chief Medical Officers for England and Wales established an Expert Advisory Group on Cancer (EAGC). Their first task has been to prepare this policy framework for commissioning cancer services. A list of members and their affiliations is at Annex A. Members of the group attend as individuals and not to represent the views of specific bodies or organisations.

## 2. INTRODUCTION

2.1 This report will serve to outline the direction in which cancer services in England and Wales should be developed. Discussion locally and nationally with purchasers, providers and professional bodies will be needed before they can be implemented. The EAGC are working with the Clinical Outcomes Group in England and the professions to develop more specific disease-related guidelines starting with the commoner cancers. Subsequent reports will be concerned with other aspects of cancer care.

2.2 Discussions have built on work already available, some going back over 20 years. This included the document *Cancer Care and Treatment Services: Advice for Purchasers and Providers* produced by the Royal College of Radiologists and Royal College of Physicians; the *Review of the Pattern of Cancer Services in England and Wales* from the Association of Cancer Physicians; the *Protocol for Investment in Health Gain* produced by the Welsh Office; the Scottish Office's *Management of Non-Surgical Cancer Services in Scotland*; and the *Report of an Independent Review of Specialist Services (Cancer) in London*. Work done recently on the provision of cancer services is useful to purchasers.

2.3 The Group especially noted the "patient centred" approach taken by the *Protocol for Investment in Health Gain* produced by the Welsh Office. The group also reviewed the substantial international literature on cancer survival in relation to patterns of care.

It was noted that improved outcomes are associated with specialised care for uncommon cancers and that many studies also suggest this association for commoner cancers. Research in this area is summarised at Annex B.

2.4 The Expert Advisory Group noted encouraging signs in the management of cancer. For example, surgical and radiotherapeutic techniques have improved with benefits to patients; there have been dramatic advances in the management of some of the less common cancers, particularly those occurring in childhood. In several common cancers the use of drug treatments has been associated with modest but significant increases in cure rates in some groups of patients. Advances in basic sciences suggest the possibility of exciting new treatments in the coming decades. There have also been significant advances in symptom palliation, particularly in pain control, and the professions involved in cancer care have sharpened their emphasis on maximising the quality of life of cancer patients. It is therefore timely to review cancer services to ensure that these benefits are made available to all cancer patients.

2.5 The Group recognise the size and complexity of their task. Cancer services involve primary, secondary and tertiary services, many charities, all of the Royal Colleges, university departments and research groups and other health care

professional bodies. Services are diverse, reflecting wide variation in the density of the population of England and Wales. Cancer services must respond to the changes in management brought about by changes to the NHS, with both purchasers and providers re-examining their patterns of cancer care.

2.6 The management of cancer will be influenced by substantial changes in the application of existing technologies (eg adjuvant chemotherapy, bone marrow transplantation, modern palliative care). Services also need to be flexible in responding to emerging technologies and new research findings such as the identification of gene carriers and molecular diagnostic techniques.

2.7 This report has been prepared following an extensive consultation with professional bodies, the National Health Service, related charities, Community Health Councils in England and Wales and other organisations. Over 300 responses were received which were generally very supportive. Key individual concerns have been carefully considered in the preparation of the final report.

2.8 The Group has welcomed the opportunity to work with other agencies in the development of a sound base for the provision of cancer care. The voluntary sector was particularly active, notably in research, palliation and patient information and support.

### **3**

## **GENERAL PRINCIPLES**

3.1 The principles which should govern the provision of cancer care are:

- i) **All patients should have access to a uniformly high quality of care in the community or hospital wherever they may live to ensure the maximum possible cure rates and best quality of life. Care should be provided as close to the patient's home as is compatible with high quality, safe and effective treatment.**
- ii) **Public and professional education to help early recognition of symptoms of cancer and the availability of national screening programmes are vital parts of any comprehensive programme for cancer care.**
- iii) **Patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards.**
- iv) **The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important.**
- v) **The primary care team is a central and continuing element in cancer care for both the patient and his or her family from primary prevention, pre-symptomatic screening, initial diagnosis, through to care and follow up or, in some cases, death and bereavement. Effective communication between sectors is imperative in achieving the best possible care.**
- vi) **In recognition of the impact that screening, diagnosis and treatment of cancer have on patients, families and their carers, psychosocial aspects of cancer care should be considered at all stages.**
- vii) **Cancer registration and careful monitoring of treatment and outcomes are essential.**

## **4. RECOMMENDATIONS**

### **4.1 THE NEW STRUCTURE FOR CANCER SERVICES**

4.1.1 The new structure should be based on a network of expertise in cancer care reaching from primary care through Cancer Units in district hospitals to Cancer Centres. In this way the Expert Advisory Group seek to ensure that the benefits of specialised care are available to all patients either close to their homes or, when necessary, by referral to special Centres.

4.1.2 This network of care is intended to deliver a uniform standard of high quality care to all patients. Integration with relevant non-cancer services is essential.

Three levels of care are proposed:

i. Primary care is seen as the focus of care. Detailed discussions between Primary Care Teams, Units and Centres will be necessary to clarify patterns of referral and follow up which will ensure the best outcomes.

ii. Designated Cancer Units should be created in many district general hospitals. These should be of a size to support clinical teams with sufficient expertise and facilities to manage the commoner cancers.

iii. Designated Cancer Centres should provide expertise in the management of all cancers, including common cancers within their immediate geographical locality and less common cancers by referral from Cancer Units. They will provide specialist diagnostic and therapeutic techniques including radiotherapy.

4.1.3 The integration of these three levels of care with each other and with non-cancer related services should provide a comprehensive cancer service. Where there are several district hospitals within an area, purchasers and providers may wish to agree together the development of the cancer unit for one particular cancer or group of cancers in one hospital and another cancer or group of cancers in another hospital.

4.1.4 Services should be planned to minimise travelling times whilst maintaining the highest standards of specialist care, using local expertise and agreed protocols. In particular, this network is one of proficiency and not of buildings. It may however be appropriate in some areas to relocate or re-build some facilities to create effective cancer services. This should

provide flexibility for future developments and changes to the management of cancer.

4.1.5 Although there will be some variations in patterns of practice across the country, Cancer Units or Cancer Centres which use different methods of treatment should be expected to justify them on scientific or logistical grounds.

4.1.6 The achievement of the changes we propose will require careful monitoring. The cancer registries have an important position in this through their ongoing registration of a comprehensive data set on all cancer patients. This allows time trends to be followed in relation to the epidemiology of the disease and treatment and survival rates to be overseen. High quality comprehensive cancer registration data enable Health Authorities, Trusts and clinicians to monitor and audit service performance.

## **4.2**

### **THE CANCER UNIT**

4.2.1 The **Cancer Unit** would normally be a district hospital with a full range of supportive services, and should agree with purchasers the range of services to be provided. **These must include arrangements for the close integration of primary and secondary care and the identification of appropriate rapid referral patterns for patients with symptoms indicating a high risk of a diagnosis of a malignancy.**

4.2.2 **It is not expected that the Cancer Unit would be separated from the other hospital services but rather that it should be an integrated part of the hospital.** The hospital should ensure site specific consultation in clinics led by consultant specialists eg breast clinic, gastrointestinal clinic. The most common cancers are initially managed by surgeons and the provision of appropriate surgical specialists to manage patients in this phase of their illness, either for their diagnosis or for the performance of a major surgical resection, is essential. The service within Cancer Units in district hospitals is in many ways surgically led and this is not likely to change in the foreseeable future.

4.2.3 Surgical sub-specialisation in the common cancer sites within the Cancer Unit is essential and a hospital should only seek to function as a Cancer Unit if the volume of work related to each cancer site is sufficient to maintain such sub-specialisation. Similar considerations apply to the work of physicians in cancer care. All specialities with responsibility for cancer care should form a network for audit with other cancer units and centres.

4.2.4 It will be necessary to allow flexibility for emergency presentations of cancers in hospitals without Cancer Units. Arrangements should however be in place for rapid referral of patients to, or liaison with, a Cancer Unit or Centre.

4.2.5 It is anticipated that the Cancer Units will only have a sufficient volume of work to provide secondary care for the commoner cancers. The exact number of cases required to justify such site specialisation will be the subject of guidelines to be developed in consultation with the relevant professional bodies. It is expected that the commoner cancers (breast, lung and gastro-intestinal) will normally be cared for in a Cancer Unit, or in a Cancer Centre for patients in the immediate geographic area. Most Units will not have a sufficient workload to justify the development of services for less common or rare cancers.

4.2.6 The presence of appropriately trained site-specialised consultant surgeons in the Cancer Unit and the development of appropriate

specialisation providing care for an adequate number of patients are fundamental. In future the surgical management of cancer should be carried out by consultant surgeons who specialise in a particular anatomical area. This work may encompass non-malignant conditions as well as cancers. This is the pattern in many hospitals at present but the development of such specialty interests as breast diseases and gastro-intestinal diseases, which are important for cancer care and for identification as a cancer unit, will have a significant impact on the organisation of surgical services in some hospitals.

4.2.7 The detailed work with appropriate professional bodies necessary to reach conclusions about the minimum acceptable volume of work in any cancer is already beginning. The Royal College of Surgeons is looking at issues of workload and specialisation and the Royal College of Radiologists is studying accreditation and quality assurance within radiotherapy centres. The Royal College of Obstetrics and Gynaecology has established training programmes in gynaecological oncology. The Royal College of Nursing has published research based *Standards of Nursing Care for Cancer Patients* and *Standards for Cancer Nursing Education* are in final draft.

4.2.8 A **lead clinician** with a well-established interest in cancer care should be appointed to organise and coordinate the whole range of cancer services provided within the Cancer Unit. Specific sessions to perform this work will be necessary. The lead clinician should be responsible for ensuring that high quality cancer services are delivered and effectively co-ordinated. Specific responsibilities should include:

- \* ensuring supervision of the facilities for cancer care;
- \* ensuring there is adequate non-surgical support;
- \* supervising arrangements for audit and for continuing medical education;
- \* meeting regularly with colleagues from other Cancer Units and Cancer Centres and general practice to guarantee uniform standards;
- \* developing protocols between primary care, Cancer Units and Cancer Centres to ensure an effective network of high standard care.

4.2.9 The involvement of the lead clinician with surgical and non-surgical colleagues in developing and maintaining the cancer service of the host hospital will be an essential element in making sure that cancer services receive adequate priority in that hospital.

4.2.10 Great importance is also attached to the integration of the work of the Cancer Units with the Cancer Centre. This can only be achieved by strong links for all the professions, common treatment policies, audit arrangements and participation in trials.

4.2.11 Multi-disciplinary consultation and management are essential and each Cancer Unit should have in place arrangements for non-surgical oncological input into services. A non-surgical oncologist (either a medical oncologist accredited by the Royal College of Physicians or a clinical oncologist accredited by the Royal College of Radiologists) who practices in a Cancer Unit should also hold an appointment at a Cancer Centre. Local arrangements will depend on cancer site specialisation by the oncologist and the Cancer Unit, but sufficient time must be available in the Cancer Unit to guarantee a firm commitment to those local oncology services. This means a minimum of five sessions of non-surgical oncology time, even in the smaller Cancer Units.

4.2.12 There are several ways in which the non-surgical oncology input might be achieved. One would be for one or more clinical oncologists with a special interest to visit the Cancer Unit. Another would be the appointment of a medical oncologist to work in the Unit as well as the Cancer Centre. Combinations of these approaches are possible. Each Unit should evolve its own pattern based on its size, the number of patients with cancers of different types treated, previous patterns of practice and staff in post and its distance from the Cancer Centre.

4.2.13 Whatever arrangement is agreed locally, the work of the non-surgical oncologist must allow the opportunity for taking part in professional education, development and audit so that current knowledge is rapidly available and disseminated within the Cancer Unit.

4.2.14 The Expert Advisory Group strongly support the initiative of the Joint Council for Clinical Oncology between the Royal College of Physicians and the Royal College of Radiologists in addressing the issue of non-surgical oncology. The essential contribution which medical oncologists from the Royal College of Physicians and clinical oncologists from the Royal College of Radiologists make to the management of cancer may overlap. The Expert Advisory Group on Cancer warmly welcome the move towards closer integration of their work and the development of core training by the Joint Council.

4.2.15 Although the development of cancer services must initially take place with specialists already accredited or in active training in these areas, the Expert Advisory Group feel that in the medium and long term, service developments would be facilitated by further collaboration between these two non-surgical oncology specialties. Representations from both Royal Colleges supporting increased numbers of consultants in each case have been made and purchasers are encouraged to consider carefully the need for appropriate manpower development in both areas.

4.2.16 Nursing care for inpatients at ward level and for outpatients in the Unit must be planned and led by nurses who have benefited from post-registration education in oncology. The nursing service must be structured to ensure access to specialist nurses:

- \* with site specific expertise, for example in breast care;
- \* with specialist skills, for example lymphoedema management and cytotoxic chemotherapy administration;
- \* with expertise in related areas, for example symptom control, post-operative analgesia, counselling and psychosocial support.

4.2.17 The services of the cancer unit should include palliative medicine consultation, access to counselling and other forms of psychological help. Supportive care, prosthetics and stoma care, appropriate complementary therapies and the encouragement of local self help groups are all important components in providing the best cancer care. Other services, such as physiotherapy, dietetics, speech therapy, occupational therapy, chaplaincy and social services should all be easily available.

4.2.18 Chemotherapy should be given only in a specified location or locations in the hospital supported by specialist staff, particularly clinical nurse specialists in oncology, and other cancer nurses. The provision of non-surgical cancer care scattered throughout hospitals by a range of different disciplines is potentially dangerous and should be discouraged.

4.2.19 The administration of chemotherapy and biological therapy is possible in the Cancer Unit for many forms of cancer. However, the Unit should seek to deliver these treatments only when it has appropriate facilities and sufficiently experienced multi-disciplinary teams. The Joint Council for Clinical Oncology has recently issued guidelines covering the quality standards that must be observed whenever chemotherapy and biological therapy are administered. Treatment protocols delivered in the Cancer Unit should be the same as those in the Cancer Centre. Where the Cancer Unit lacks facilities to provide these safely, patients should be transferred for that phase of their management to the Cancer Centre.

4.2.20 Radiotherapy should normally be confined to Cancer Centres. In localities remote from a Centre, purchasers will need to consider the case for existing Cancer Units continuing to provide limited radiotherapy services in close collaboration with a Centre.

4.2.21 The size of a population served by a Cancer Unit cannot be inflexibly defined but will be determined by the number of cases of each cancer type being seen there, related to professional guidance on the number of cases necessary to develop and maintain expertise. Not all district hospitals will be Cancer Units. Their location will be influenced by the distance of that population from a Cancer Centre and from other Cancer Units.

4.2.22 Development of the Cancer Unit will present an opportunity for integration with haematological oncology services provided by haematologists in district hospitals. Where there is an established haematological oncology service, it may be incorporated into the Cancer Unit and some nurses with training in oncology used for patients with haematological cancers and solid tumours. It is important to avoid duplication and waste of resources between the facilities available for haematological malignancies and those for solid tumours. Similar considerations about the number of cases treated to ensure adequate expertise will apply to haematological oncology as to solid tumours.

4.2.23 The Cancer Unit should have a special responsibility for integration with the primary sector, with multi-disciplinary palliative care services and rehabilitation services which should be provided as close as possible to the patient's home. There must also be clear routes of liaison and referral to palliative care and rehabilitation services, to allow access for in-patients and out-patients in the Cancer Unit.

4.2.24 The Cancer Unit will have an important role in Education and Research. All trainees in oncology must be trained in the management of patients in a Cancer Unit. Cancer Units will be expected to become involved in appropriate clinical research and the development of diagnostic and support services. Within district hospitals with Cancer Units there will be significant implications for the development of clinically related services, particularly haematology, pathology and radiology.

## **4.3**

### **THE CANCER CENTRE**

4.3.1 The **Cancer Centre** should ideally be part of a large general hospital providing services for patients with commoner cancers in the same way as the Cancer Unit, as well as an additional range of specialised services which it will normally provide in support of Cancer Units. Contractual arrangements should be reached by purchasing authorities with a Cancer Centre. The Cancer Centre should deliver a full range of cancer treatments to encompass treatment programmes for less common and rare cancers and those treatment regimens which are too specialised, technically demanding or capital intensive to be provided in the Cancer Unit. A small number of very rare cancers (eg choriocarcinoma) should be managed in a small number of Cancer Centres to ensure adequate specialisation.

4.3.2 Specialisation in cancer sites should be further developed in the Cancer Centre both for diagnosis and treatment: surgeons and physicians with special skills should practice here. The opportunity for specialised multi-disciplinary consultation for patients will be available for almost all types of cancer.

4.3.3 Links with other specialists from non-cancer areas will ensure a full range of support and rapid deployment of new techniques which are relevant in many areas.

4.3.4 Definitions of the Cancer Centre have been developed by several bodies. The hallmarks of a Cancer Centre are a high degree of specialisation and comprehensive provision of all of the facets of cancer care necessary in modern cancer management. The London Implementation Group recommended that Cancer Centres be defined as those with eight or more non-surgical cancer specialists to ensure an adequate range of site specialisation. It has been recommended that these Centres should serve a population of at least 1,000,000, though this remains under review. This was a development from the Royal College of Radiologists' recommendations that Cancer Centres should serve a population of a minimum number of two-thirds of a million people.

4.3.5 Nursing care in the wards and departments of a Cancer Centre should be planned and delivered by nurses with a post-registration cancer qualification or who are in the process of gaining such a qualification.

Clinical Nurse Specialist skills include:

- \* Intravenous Cytotoxic Chemotherapy
- \* Palliative Care

- \* Breast care
- \* Rehabilitation/Psychosocial support
- \* Lymphoedema Management
- \* Stoma Care

The Cancer Centre should also commit itself to providing advanced cancer nursing education for those within and outside the centre.

4.3.6 Therapy radiographers within a Cancer Centre need a wide range of skills: technical expertise to deliver the day to day radiation treatment, counselling and supportive care of patients during the course of their treatment, and managerial skills to ensure a safe and efficient service. Therapy radiographers should hold at least the approved qualification of the College of Radiographers.

4.3.7 The Expert Advisory Group recognise that it is impracticable to devise a satisfactory single blueprint for a Cancer Centre but the essential element defining such a Centre is the expertise of the health care professionals concentrated within it. It is this which has to be comprehensive and of high quality. Expertise in the management of rare cancers will only be achieved by the degree of site specialisation and multi-disciplinary care available in the Cancer Centre.

4.3.8 Although the Expert Advisory Group believe that a Cancer Centre will normally serve a population of more than 1,000,000, careful consideration of geographical constraints will always be necessary to ensure a balanced service. A population base of two-thirds of a million should however be considered an absolute minimum.

4.3.9 The services that will be a feature of most Cancer Centres are readily identified:

- \* Paediatric and adolescent cancer services. All populations should have access to these services
- \* The assessment and management of rare cancers in multi-disciplinary teams and the accumulation of expertise in these treatments
- \* Specialist surgical services including plastic and reconstructive surgery
- \* Intensive chemotherapy particularly involving complex haematological support such as bone marrow transplantation and peripheral blood stem cell support

- \* A full range of radiotherapy facilities with appropriate numbers of clinical oncologists to ensure specialised application

- \* Medical oncology

- \* Sophisticated diagnostic facilities (pathology and imaging)

- \* Special expertise in palliative care and rehabilitation.

4.3.10 The range of services in the Cancer Centre will depend upon the pattern of service within local Cancer Units. Local Units should transfer care to the Centre either for the entire management of patients with particular malignancies or for part of the management of those patients if the Units are unable to provide the required protocols for treatment or where the volume of work is too small to justify its provision in the Cancer Unit.

4.3.11 In some regions it is possible that all cancers of certain types will be managed in the Cancer Centre for either surgical or non-surgical anti-cancer treatment, with patients returning to local Cancer Units for follow up.

4.3.12 The Cancer Centre represents a centralisation of expertise of many disciplines and it is desirable that it should be brought together in one hospital or by one administrative structure. However, a network for provision of care to obtain adequate expertise drawing on different hospitals might be unavoidable in some parts of the country. In some cities, it may be necessary to involve several hospitals including those from different provider Trusts to ensure that sufficient expertise is drawn into the Cancer Centre.

4.3.13 Where it is not possible to concentrate all expertise in one site, close collaborative structures and managerial integration are needed with the identification of lead clinicians appointed to ensure the development and function of the Centre. This will ensure multi-disciplinary team working, allowing staff with particular skills to be identified.

4.3.14 The Cancer Centre has an important role in training, continuing medical education and clinical audit for health care professionals.

4.3.15 Research and development and the entry of patients into clinical trials should be the responsibility of the entire network of Cancer Units and Centres. Although research laboratories and the coordination of trials would be expected to be mainly the business of the Cancer Centre, the entry of patients into trials should be the responsibility of the whole network and specialists working in Cancer Units may well take a lead in research

initiatives.

4.3.16 The balance of practice between the Cancer Units and the Cancer Centre must vary in different regions reflecting the distribution of the local population, existing services and local expertise. The balance would also be expected to change over time as new treatments become available. These are likely to be technically demanding at first and therefore should initially be delivered only by the Cancer Centre. With further development however, new treatments should in time become available in the Cancer Units.

4.3.17 As with Cancer Units, there will be significant implications within hospitals which accommodate Cancer Centres, for the development of diagnostic and support services and clinically related services, particularly haematology, pathology and radiology.

## **4.4**

### **CHILDREN AND ADOLESCENTS WITH CANCER**

4.4.1 A network of Centres providing services in paediatric oncology exists. The maintenance of this network, its integration with Cancer Centres and the provision of specialist nursing in paediatric oncology must remain a high priority for purchasers. They will need to build on progress already made to ensure that all children are treated within paediatric specialist centres and that children's hospices have direct links with these centres.

4.4.2 Purchasers should look for opportunities for developing the treatment of adolescents with cancer. They present special medical and psychological problems and require specialised care in the Cancer Centre. The development of Centres for the care of adolescents with cancer is less complete and refurbishment, or in some instances new building, may be necessary.

## **4.5**

### **PALLIATIVE CARE**

4.5.1 Palliative care should not be associated exclusively with terminal care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis. The palliative care team should integrate in a seamless way with all cancer treatment services to provide the best possible quality of life for the patient and their family. The palliative care services should work in close collaboration with their colleagues at the Cancer Centre and be involved in regional audit and developing integrated operational policies and protocols.

4.5.2 Although much palliative and terminal care is provided in the community by primary care teams, each district must have a specialist resource for both primary care and hospital based services. This facility should work with local hospital oncology services and with primary care teams to allow good communications and rapid access to specialised palliative treatments for symptom control, to provide respite care and to give psychosocial support to the patient and family at all stages, including bereavement. By this means, there should be a smooth progression of care between home, hospital and hospice.

4.5.3 The multi-disciplinary palliative care team should contain trained specialist medical and nursing staff, social workers, physiotherapists, occupational therapists and should relate to other disciplines such as dietetics and chaplaincy.

4.5.4 Patient facilities should be such as to ensure privacy and dignity through the provision of private rooms for confidential discussions, and facilities to allow relatives to remain with very ill patients. Spiritual care of patients must be available when required.

4.5.5 Hospice units have sometimes developed in an ad hoc fashion through voluntary effort and fundraising. As a result, links with health authorities and purchasers are under-developed in some areas. The quality standards and operational policies being developed by leading palliative care units and the National Council for Hospice and Specialist Palliative Care Services should be widely adopted to ensure high standards of care and integration with cancer care services to meet patient need. Where new developments are proposed, providers consulting with purchasers should assess local needs to ensure that services will not be duplicated, that current services are being used to best advantage and that the new service will improve liaison and satisfy unmet needs in patient care. New developments must not remove resources from established palliative care units which are delivering high quality care.

## **4.6 THE RELATIONSHIP OF CANCER SERVICES WITH PRIMARY CARE**

4.6.1 The close relationship between primary care and secondary care services within the Cancer Unit and the Cancer Centre has been emphasised in these recommendations. The development of Primary Health Care Teams will enhance patient care.

4.6.2 The relationship should be one of partnership in continuing care rather than the permanent or temporary transfer of responsibility for the patient.

4.6.3 In order to judge the quality of care provided by their local cancer services, GPs (both fundholding and non-fundholding) will require information about what constitutes "best care", organisationally and for individual cancers.

4.6.4 Local guidelines for the identification and management of symptoms that indicate a high risk of malignancy need to be established for each cancer, with reference to nationally agreed and rigorously evaluated standards.

4.6.5 The cancer services need to establish local referral patterns in co-operation with primary care. These should be flexible, recognising the extent to which many GPs will wish to be involved with the diagnostic process.

4.6.6 Secondary and tertiary care services must recognise that, simultaneously with their medical management of the patient, primary care is providing psychological and emotional support, acting as link and advocate with the secondary and tertiary sectors, providing and translating information, and dealing with parallel non-cancer illnesses.

4.6.7 The importance of communication, appropriate in time and content, between primary care, and the specialist services can not be over-estimated. Any changes in patient management should be made known to all involved in their care. As with referral, local procedures for this need to be established.

4.6.8 Discharge information should reach relevant members of primary health care teams on the day of discharge; this should include details of diagnosis, a management plan, including drugs, other agencies involved and information given to the patients and their families.

4.6.9 Primary Health Care Teams must ensure that clinical changes are notified to the key specialist services prior to the next patient contact.

The interface between primary and secondary care is important for purchasers (DHAs and GPFHs) and for general practitioners more widely. Moves that improve the continuity of care are welcome and of particular importance for patients with long term illnesses such as cancer. The prime concern must be the appropriateness of services at each level and the capability to ensure their quality, in particular the expertise of those involved. Cancer Units, and especially their lead clinician, will have an important role in devising ways to ensure quality locally.

## **4.7**

### **THE DEVELOPMENT OF THE PURCHASING PROCESS**

4.7.1 The development of appropriate contracting for services is a crucial issue. This should enable purchasers and providers to initiate changes designed to make specific improvements in services. The form of contracts, as well as the mechanisms for monitoring performance, strongly influence what can be achieved in practice.

4.7.2 At present, in most contracts, many cancer services are not clearly identifiable because they form part of more general contracts, for example for surgical services. In this clinical area, as in others, the extent to which the overall contracting process becomes capable of discriminating between the management of different diseases, and the detailed needs of particular groups of patients, will help to determine the degree to which these recommendations are successfully implemented.

4.7.3 Ideally contracts should be developed to cover each individual cancer site. An early step might be to take a common tumour, or organ based groups of diseases (such as GI tract, urological or haematological malignancies) and use them as local models to build understanding and gain experience in contracting techniques. An illustrative framework for this is set out below in a form consistent with the general thrust of this document. Five issues are suggested for explicit reference within contracts, and subsequently as topics for the performance monitoring of those contracts.

i. Arrangements, which might include agreed protocols, for referral and diagnosis of particular malignancies, and hence of important common precursor symptoms.

ii. Documented systems for the coordinated delivery at the local level of information, support and care between the Cancer Unit, the primary health care team and any outside providers of community services, palliative or terminal care.

iii. The effective and coordinated management of treatment at the Cancer Unit and the Cancer Centre. This requires clear documented policies for onward referral, management of the different components of treatment and the provision of specialist oncology expertise at the Cancer Unit.

iv. The adoption of measures for the assessment of provider performance. This includes appropriate results from clinical audit, and from cancer registries.

v. The adoption of suitable standards for prevention and early diagnosis services relating to the population they serve.

4.7.4 A first step for purchasers should be to review local hospital services in order to identify those that will continue as Cancer Units. This exercise must be carried out with appropriate multi-disciplinary professional advice and must involve providers. Wider community perspectives will also need to be drawn into the process. A range of interested local organisations will exist in most places.

4.7.5 On a similar basis the identity and role of the Cancer Centre serving the purchaser, will need to be defined. The Cancer Centre is concerned with the resources and expertise for the management of complex cases and less common diseases. It is in purchasers' interest to collaborate in developing their approach to the role of Cancer Centres as well as the management of common cancers for their local population.

4.7.6 The deployment of specialist oncologists in Units and their links to the Regional Centres are critical to the working arrangements at both Units and Centres. The Expert Advisory Group see this as a very important area for development.

## **IMPLEMENTING THESE RECOMMENDATIONS**

5.1 The Expert Advisory Group on Cancer are particularly concerned to see their recommendations implemented so that all patients have access to a uniformly high standard of care and the opportunity to benefit from effective new treatments as they become available. Decisions will have to be taken forward in the light of local circumstances and take account of the views of patients and their carers as well as the professionals involved in providing care, informed by available scientific knowledge and research and development. The Group recognise that the development of the ideal pattern of service should build upon existing patterns of referral and care and should take account of geographical constraints. Although acknowledging that some changes will take time, the EAGC would wish purchasers to move swiftly to develop plans which will take account of these recommendations.

5.2 Many hospitals providing radiotherapy services in England and Wales do not conform to the definition of a Cancer Centre. In some cases the continuation of radiotherapy treatment in these locations will be justified because of their distance from a Cancer Centre. In such cases, these hospitals will be Cancer Units with radiotherapy facilities. It is essential that they are closely linked to a Cancer Centre by common treatment protocols, shared audit and professional communication and development. Where there is no geographical justification for continuation in this form, purchasers should work with providers to ensure the evolution of these services towards the provision of a Cancer Unit. The implementation of quality assurance in radiotherapy services as set out in "*Quality Assurance in Radiotherapy*" is important.

5.3 The EAGC believe that the NHS Executive and the Welsh Office Health Department should include these recommendations in planning guidance at the earliest opportunity and purchasers should move to identify their Cancer Centres and their Cancer Units. Professional advice from all disciplines will be necessary in forming plans, particularly in relation to the number of cancer patients to be managed in a Cancer Unit to ensure adequate expertise.

5.4 The primary sector is of vital significance in the provision of high quality cancer care, in diagnosis, appropriate referral, treatment and support. The relationship between primary and secondary care is, therefore, a key element in the successful implementation of these recommendations. The Health Departments and professional bodies will need to ensure that the primary sector is fully involved in moves towards the new structure for cancer services.

5.5 Some specific service developments will be required. Professional organisations have emphasised the need for the provision of oncology specialists: this will be essential in developing the network of Cancer Units and Cancer

Centres. Some increases in the numbers of health care professionals involved in cancer care will be necessary. They should be strategically placed to ensure the best service developments. Any such developments should be fully evaluated in their first few years to ensure that they are effective and that they lead to the implementation of these recommendations. The need for new resources is likely to be incremental over a period of about five years. The provision of one postholder training posts ( the post exists only for as long as it takes to train the postholder) to produce adequate numbers of consultants to fill the required posts in medicine and adequate numbers of specialists from other health care disciplines is an approach that the EAGC would like the NHS Executive and the Welsh Office Health Department to consider.

5.6 Research and Development to evaluate aspects of cancer care will be necessary. Topics may be identified by the Research and Development Directorates for national, regional or local funding.

5.7 The minimum number of patients managed in a Cancer Unit by individual specialists to a satisfactory standard of care needs to be determined. Work to that end - to which professional organisations should contribute - should proceed rapidly.

5.8 The use of Clinical Audit in Cancer Units and Cancer Centres in association with Cancer Registries will be important to monitor the development of the service network and its function.

5.9 The Expert Advisory Group believe that purchasers have a crucial role in developing a uniformly high quality of cancer care for all cancer patients in England and Wales and for ensuring that patients have access to, and can benefit from, new management approaches as they emerge in coming years.

5.10 The NHS Executive and the Welsh Office Health Department should develop networks for the implementation of these recommendations. They should work with the Expert Advisory Group to develop ways of monitoring the effectiveness of the changes resulting from the recommendations in improving patient care and report regularly to Ministers.

5.11 The Expert Advisory Group and the Welsh Office Health Department would like to work with the NHS Executive to develop ways of monitoring implementation and to receive reports from them on progress made.

## **6      SUMMARY OF RECOMMENDATIONS AND ACTION POINTS**

- i. All cancer patients should have access to a uniformly high standard of care.
- ii. The needs of patients and their carers should be the primary concern of purchasers, planners and professionals involved in cancer services.

### **ActionPurchasers, Provider Units and Professional Bodies.**

- iii. Cancer Centres and Cancer Units should be established to provide an integrated network of cancer care. Effective communications between components, including communication between Cancer Centres are vital.

### **ActionPurchasers, Cancer Units and Cancer Centres as they are identified.**

- iv. There should be a clear understanding of appropriate referral and follow up patterns between General Practitioners, Cancer Units and Cancer Centres. These should be based on agreed guidelines and information on quality and outcome of care and should involve patient groups.

### **ActionCommissioning authorities to facilitate discussion between GPs, Patient Groups, Units and Centres.**

- v. Cancer Units should appoint a lead clinician to coordinate services for cancer patients in a Unit. The lead clinician should be closely involved in negotiating service agreements with purchasers.

### **ActionCancer Units.**

- vi. Professional bodies should urgently develop guidance on the level of expertise and support required to manage the commoner cancers.

### **ActionHealth Departments and Professional Bodies.**

- vii. The Health Departments to work with professional bodies in developing the role of Primary Health Care Teams in the management of cancer.

### **ActionHealth Departments and relevant professional bodies**

- viii. Each Cancer Unit will need to have input from non-surgical oncology. Development of appropriately trained staff will take several years. We welcome and encourage the collaboration between medical and clinical oncologists.

**Action Royal College of Physicians and Royal College of Radiologists.**

ix. There are manpower implications for all specialties and professions involved in cancer care. Discussions should be held with appropriate professional bodies.

**Action Health Departments and professional bodies to coordinate.**

x. Radiotherapy should normally be provided in a Cancer Centre. In exceptional geographical circumstances it may be necessary to continue to provide radiotherapy in Cancer Units closely linked to Cancer Centres for existing quality assurance and audit purposes.

**Action Purchasers and providers to identify radiotherapy centres that need to be outside Cancer Centres and to ensure that they have close links with a Cancer Centre.**

xi. Palliative care and symptom control should be available at all stages of a patient's illness. Hospitals, primary care, social services and the voluntary sector should all be involved.

**Action Commissioning authorities should develop a local plan for delivering palliative care, bringing together all providers.**

xii. Education, audit, research into cancer care and the entry of patients into trials are important parts of the programme.

**Action Royal Colleges, Purchasers, Providers, University Departments and Charities.**

xiii. **The full changes in the organisation and provision of cancer services recommended in this report will take several years to implement. There is however much that can be done now** by better organisation and improved communication between patients, purchasers, providers and professionals and the voluntary sector to enhance the quality of cancer care and the utilisation of staff already trained. Specialist training of an oncologist takes up to five years and this assumes there are sufficient numbers of qualified doctors wishing to enter training and sufficient trainers available.

xiv. It is vital to monitor outcomes of treatment and the implementation of changes in services. The EAGC should in association with NHS Executive and Welsh Office Health Department monitor the implementation of these recommendations and report regularly to Ministers.

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**HOSPITAL BASED CANCER SERVICES**

**THE RELEVANCE OF SPECIALISED CARE**

1. **Background**

1.1 For their analysis of the evidence on optimal cancer services in preparation of the document "A Policy Framework for Commissioning Cancer Services", the Expert Advisory Group on Cancer had access to two sources of information: the medical literature and audit data provided by UK Cancer Registries.

1.2 Although the literature on cancer services is quite extensive, they do not lend themselves to controlled experiments and most information comes from retrospective analyses. The expert group recognised that this limits the conclusions that can be drawn from the published data.

2. **Limitations of the scientific evidence**

2.1 Retrospective analyses are subject to a number of possible flaws and biases:

- the population studied must be relevant to the question being asked.
- conclusions drawn from a selected group of patients referred to a single centre may not be relevant to a general and unselected population.
- the cases being studied may be an unrepresentative sample

2.2 Case selection in determining results is important. Patients with small volume localised disease have a better prognosis than those who have a large amount of cancer, widely disseminated. Case selection by cancer services is often systematic and can lead to biases:-

- referral to specialised centres at a distance may require that patients be fit. Only fit patients will therefore be represented in the case mix of those specialised centres.
- specialised centres may receive cases that are especially difficult and challenging. It is therefore possible that their prognosis is worse than for the less difficult or less challenging patients who might be managed in a district hospital setting.

The importance of determining case mix and correcting for this has not been always recognised.

### 2.3 Survival rates may be associated with socio economic status.

- routine data collected by insurance companies indicate that socio-economic status and health insurance coverage in the US are associated with improved survival (Karjalainen and Pukkala 1990, Ayanian et al 1993) and UK studies support this observation (Carnon et al 1994).

- US data suggests that educational status and income may have an independent influence on survival from different cancers (Cella et al 1991).

- differences in mortality between social classes do not necessarily reflect different outcomes after treatment. Cancer of the cervix in South Thames, showed no major differences in relative survival from this disease by class or marital status. Differences in mortality appear to reflect differences in incidence through exposure or susceptibility to aetiological agents rather than differential survival (Murphy et al 1990).

2.4 Even when the nature of the case mix is documented and corrections are made statistically, such studies can still be misleading. It is not possible to statistically correct for differences between groups which are not defined by known prognostic variables. Population based studies, have major advantages but there are few of these.

## 3. **Outcome Measures - Survival and Quality of Life**

3.1 The literature is concerned with survival as an outcome in assessing patterns of cancer services. Clearly survival is a most important outcome and it is data on this which is normally collected by registries. However, in providing high quality cancer care, survival is by no means the only outcome of importance. Patients are interested in the quality as well as the quantity of their survival and it is likely that different patterns of care will be associated with differences in quality of life. The studies to date have not addressed the measurement of quality of life in relation to cancer services although assessment of QL has become routine in some specialised units and in prospective trials.

3.2 Studies have been focused on the benefits of "specialist care" for cancer patients. There are many elements within specialist care including the training and expertise of the individual health care professionals, the breadth of the multidisciplinary team available to look after the patient, the volume of work undertaken by a Unit (higher volumes are generally but not exclusively associated with greater specialisation) and the provision of care within teaching or non-teaching hospitals. Studies which have sought to assess care have often considered only one of these aspects of specialisation.

#### 4. **Rare Cancers**

4.1 Studies in paediatric cancers and in rare cancers in adults, particularly testicular cancer, have been published and show consistent advantages to the management of these cancers in specialist centres (Stiller and Bunch 1990, Stiller and Draper 1989, Aass et al 1991, Harding et al 1993). In these studies, important aspects of the skills associated with the specialist units which determined successful outcomes were identified including adequate delivery of treatment doses for chemotherapy, a larger volume of work and adherence to protocols.

#### 5. **Moderately Common Cancers**

5.1 Studies of ovarian cancer have been carried out by a number of groups (Gillis et al 1991, Gillis 1993, Junor et al 1994, Kehoe et al 1994) and all of these studies show that care being delivered by a gynaecologist resulted in a better outcome than care delivered by a general surgeon, even when careful multivariate techniques were used to correct for case mix. Unpublished audit information suggests that there was a close relationship between the number of patients treated by an individual surgeon and outcome (Gillis et al, unpublished).

5.2 In haematological malignancies there is evidence for advantages for specialist care in multiple myeloma (Karjalainen and Palva 1989) and Hodgkin's disease (Davis et al 1987).

5.3 For oesophageal cancer, gastric cancer and pancreatic cancer (Matthews et al 1986, Gulliford et al 1993, Edge et al 1993, McArdle and Hole 1991) successful immediate outcomes of surgery were associated with a larger throughput of surgical cases although this effect may have been reduced in oesophageal cancer in recent years (Gulliford et al 1993).

#### 6. **Common Cancers**

6.1 For patients with breast cancer it is clear that there is a wide variation in the pattern of care available in different hospitals. In the United States adherence to agreed consensus guidelines is greater in hospitals which have a greater volume of cases (Hand et al 1991). Patterns of care are different in teaching hospitals compared to non-teaching hospitals (Basnett et al 1992, Wolfe et al 1993) and wide variations in patterns of care exist between UK district health authorities as shown in studies of 27,00 patients in Yorkshire (Sainsbury et al 1994). The differences between outcomes was associated with the adoption of hormone and chemotherapy in these studies (Haward et al 1994). Improved outcomes for breast cancer patients in university central hospitals were shown in large Finnish studies (Karjalainen 1990). German comprehensive Cancer Centres have better results for breast cancer than other hospitals (Ebeling et al 1982). Not all studies have confirmed the impact of

"specialised care" in breast cancer (Bofetta et al 1993) but none has ever shown a disadvantage from specialised treatment.

6.2 An important audit of breast cancer care carried out in the UK prospectively identified surgeons by peer review as having specialist skills in the management of this disease. The surgeons treated 2,745 women with breast cancer from a general population of 1.2 million. It was found that those surgeons identified as having specialist skills had significantly improved survival in their patient populations at five and ten years after treatment. At five years patients treated by the specialists had an 8.9% better outcome in survival and this persisted to 10 years when the improvement was 7.6% even when corrected for case mix (Gillis et al, submitted for publication).

6.3 Studies of colorectal cancer in the UK show considerable variation in surgical outcome (McArdle and Hole 1991) and Scandinavian studies suggest that university hospitals have better survival rates than general hospitals (Hakama et al 1989). This study suggested an approximately 10% increased chance of survival for patients managed in central districts with cancer centres and medical schools. Similar results were found in Germany (Mohner and Sislow 1990) and in France (Launoy et al 1992). However, declared specialists working in district general hospitals in the North West of England were able to produce similar results to declared specialists in colorectal cancer work in teaching hospitals (Kingston et al 1992). This last study suggests that high quality specialist services can be successfully established in district hospitals when specific commitments to them are made.

## 7. Conclusions

7.1 The literature, supplemented by registry studies, indicates significant improvements in survival as a result of specialist care for a number of cancers both common, moderately common and rare. Not all of the studies have been able to adjust adequately for clinical case mix and not all were population based. Numbers are restricted in many studies and not all of the important aspects of patient management have been studied in all studies, presumably because of an inadequate database. This makes it difficult to identify those aspects of specialist care which are most important in each cancer type. These will differ between cancers. For instance, colorectal cancer outcomes may be critically dependent on the technical skill of the surgeon; breast cancer outcomes may depend more on the mobilisation of a broad experience of physicians and surgeons.

7.2 The available literature and Registry data support the case for a specialised cancer service although further work is needed in some cases to define exactly those aspects of such service which are critical for each cancer.

7.3 The data suggest that the impact of specialised care for common cancers, and probably for many cancers, can increase long term survival by 5 - 10%, a very important clinical outcome.

**Peter Selby**  
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