

CANCER SERVICES

INVESTING
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1. INTRODUCTION

1.1 Introduction

1.1.1 Cancer is a significant cause of mortality and morbidity. In 1993 it was responsible for the deaths of 3,624 people in Northern Ireland. This makes it second only to heart disease as the leading cause of death. The commonest cause of cancer death is lung cancer, followed by colo-rectal cancer (cancer of the lower bowel) and breast cancer.

1.1.2 The number of deaths due to cancer rises rapidly after the age of 40. It reaches a peak in the 70-80 age group and then falls as the number of elderly people in the population decreases. Half of all cancer deaths occur in people aged over 70 years old. Most cancers are therefore more common in older people, although some occur also in younger people, for example, leukaemia, bone and brain tumours.

1.1.3 Throughout the 20th century the number of deaths due to cancer has risen steadily from 1,224 in 1912 to 3,624 in 1993. If this trend continues, the Northern Ireland Cancer Registry has estimated that there may be over 4,100 deaths due to cancer in Northern Ireland in the year 2000, accounting for 27% of all deaths. This increase in the number of deaths can be explained partly by:

- the rising elderly population, as most cancers are more common in older people;
- better diagnosis;
- more accurate recording of the cause of death; and
- changes in exposure to risk factors, for example, smoking and diet.

There is also evidence of a real increase in the incidence of some cancers, for example, malignant melanoma.

1.1.4 Many cancers are preventable. We know, for example, that 90% of lung cancers (and 30% of all cancers) are caused by smoking. Given current smoking rates, it is estimated that 25,000 teenagers in Northern Ireland today will die from smoking related diseases in middle age. A further 25,000 will die from such diseases in later life. Other measures such as screening for breast and cervical cancer as well as the earlier diagnosis of lung cancer, have a major part to play in reducing the cancer rate. The Working Group welcomed the designation of cancer as a key area within the Regional Strategy and commended its objectives.

1.1.5 Considerable progress has been made over the past few decades in the treatment of some cancers. In the case of childhood leukaemia improvements in treatment have resulted in the cure rate being improved over the past 30 years from 25% to 55%. This cure rate is still rising. Effective treatment is also possible for an increasing number of adult cancers. However, treatments are becoming more complex.

1.2 Context

1.2.1 While progress has been made in the treatment of many cancers, professional concern has been expressed at evidence that variations in the outcome of treatment may result from the organisation of local services. The debate on cancer services provision at national level has been significantly advanced by the Report of the Expert Advisory Group on Cancer, "A Policy Framework for Commissioning Cancer Services" (the Calman/Hine Report). The Expert Advisory Group on

Cancer (EAGC) was established by the Chief Medical Officers of England and Wales in view of the rising incidence of cancer and the need to develop a network of care which would enable the patient, wherever he or she lives, to receive a uniformly high standard of treatment and care. The report recommended three levels of care for patients with cancer. These were:

- primary care, which would act as the focus of cancer care;
- cancer units, where commoner cancers would be managed; and
- cancer centres, which would act as cancer units to their local population in addition to providing a regional service for rarer cancers or cancers requiring more specialised treatment.

The Report was accepted by the Secretary of State for Health and published in April 1995. It was designed to help commissioners and providers of services to make well informed decisions regarding the future organisation of cancer services. Although the Report related only to England and Wales, there was extensive consultation within Northern Ireland and widespread support for its principles and recommendations.

1.3 Cancer Working Group: Remit and Membership

1.3.1 It was against this background that the Department of Health and Social Services established a Cancer Working Group to consider how the recommendations contained in the Calman/Hine report on cancer services might best be implemented in Northern Ireland.

1.3.2 The Group was appointed by the Minister in July 1995 to:

- review the current provision of surgical and non-surgical cancer services in Northern Ireland
- consider the implications of the report of the Expert Advisory Group on Cancer for Northern Ireland in relation to current provision and the Regional Strategic Plan
- consider any quality standards in cancer services which are produced nationally
- make any recommendations to the Department by 31 March 1996 as to how services for cancer can be improved in Northern Ireland, including the clinical standards appropriate for a cancer centre and cancer units.

1.3.3 Members of the Working Group were chosen for their potential contribution as individuals and not as representatives of particular interests. The membership of the Group is given at **Appendix 1**.

1.3.4 The Working Group fully endorsed the general principles and recommendations from the Calman/Hine report. For ease of reference these are set out in **Appendix 2**.

1.4 Method of Working

1.4.1 In order to inform the work of the Group, it was decided to establish sub-groups on breast cancer, colo-rectal cancer, gynaecological cancer, lung cancer, urological cancer and palliative care. These specific sub-groups were chosen in order to determine a model of care that could be applied to other cancers. No attempt was

made to undertake a comprehensive review of the management of all cancers. The sub-groups comprised a mix of health professionals and managers and consumer interests and were chaired by members from the Cancer Working Group. Reports on the provision of services, including recommendations for future service delivery, were completed by each of the sub-groups and are detailed in Part II of this report, which has been published separately.

1.4.2 The Group believed from the outset that it was of critical importance to draw on the views and insights of others. The Chairman wrote to all acute hospitals in Northern Ireland informing them of the Group's work and inviting them to submit views on cancer services. At the same time the Group considered it important to consult the views of consumers and invited some consumer organisations working with cancer patients to submit evidence. A list of those who provided oral/written submissions is at **Appendix 3**.

1.4.3 The Group also examined reports, papers and other literature relevant to its task. A bibliography is at **Appendix 4**.

1.5 Structure of the Report

1.5.1 The report is divided into a further four sections as follows:

Section 2 describes the current provision of cancer services in Northern Ireland;

Section 3 discusses the need for change in service provision and considers evidence from the sub-groups; the benefits of specialist expertise and teamwork; advances in chemotherapeutic services; public expectations and the Regional Strategy;

Section 4 discusses proposals for the provision of cancer services in Northern Ireland and focuses on primary care, cancer unit care, cancer centre care and palliative care; and

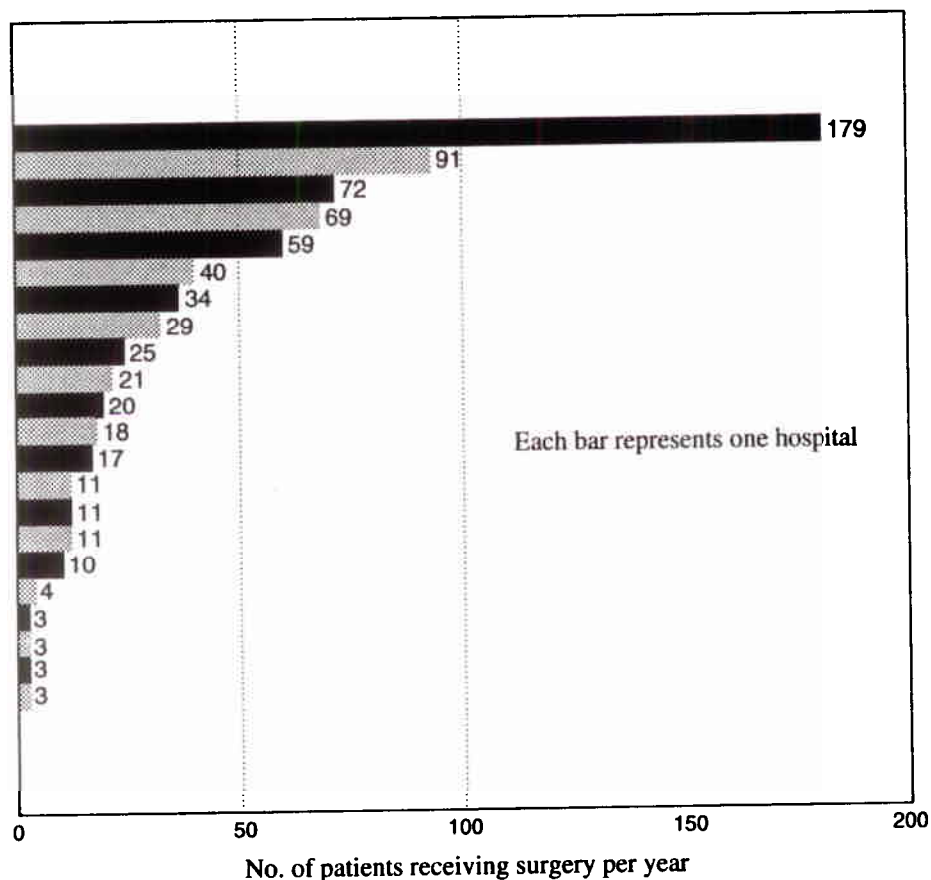
Section 5 summarises the Group's recommendations for cancer services in Northern Ireland.

2. CANCER SERVICES IN NORTHERN IRELAND

2.1 Cancer Services in Northern Ireland

- 2.1.1 To date the Department of Health and Social Services has not issued specific guidance on the delivery of cancer services. At present all acute hospitals in Northern Ireland provide cancer services to varying degrees. There has been a tendency for the rarer cancers to be treated centrally and for the more common cancers to be treated in a variety of locations.
- 2.1.2 Virtually all surgeons in Northern Ireland are engaged in cancer surgery, but there is a considerable variation in the extent of their involvement. Some consultants have developed a special expertise in cancer whilst others treat cancer as part of their normal workload. This has resulted in a very wide variation in the amount of cancer surgery carried out by surgeons and in different hospitals.
- 2.1.3 A survey of all general surgeons in Northern Ireland showed that around 70% had undertaken a surgical procedure relating to breast disease in 1995. Of these 39% had performed fewer than ten breast biopsies for suspected cancer.
- 2.1.4 A similar pattern of service provision is revealed by examining routine data. The graph below shows the number of operations for breast cancer carried out in individual hospitals over a one year period between 1993 and 1994.

HOSPITAL CASELOAD: BREAST CANCER SURGERY

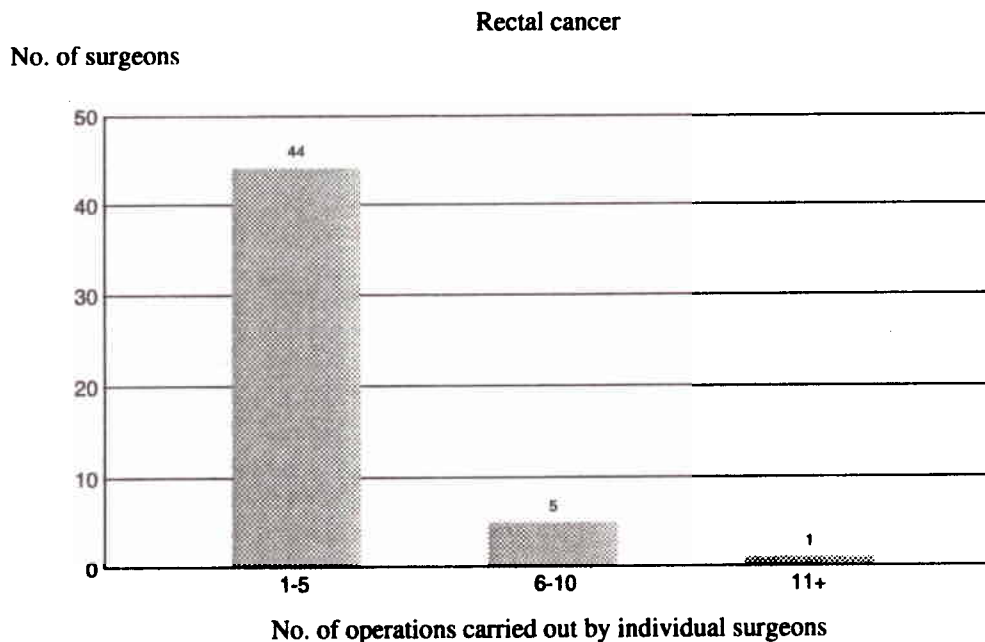


These figures cover primary diagnosis ICD9-174
and primary operations OPCS-4 B27 and B28.

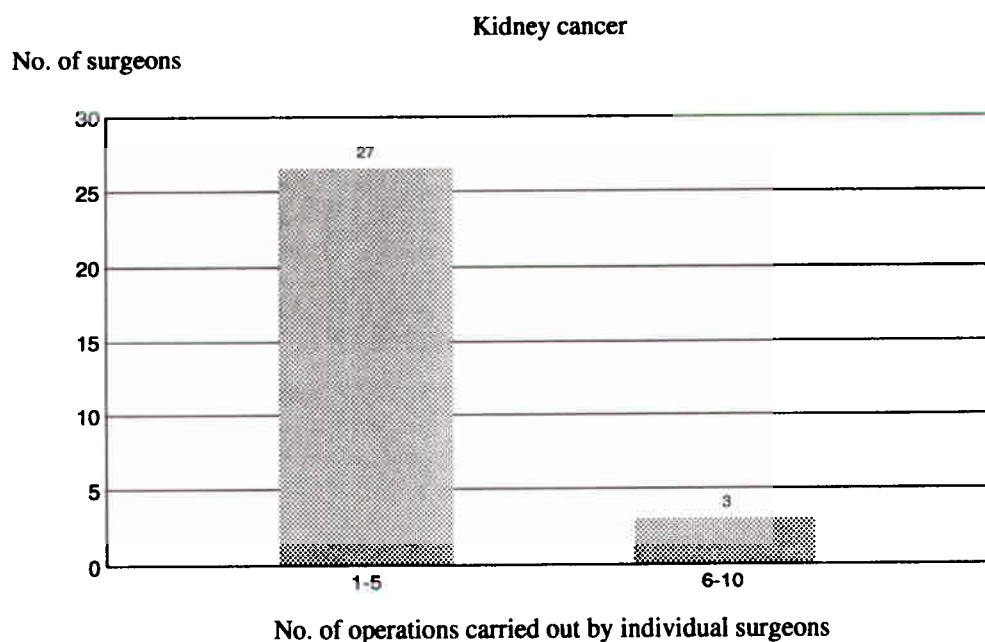
This cancer workload is further divided up amongst the consultants working within each hospital. The 733 operations described above are recorded as having been carried out by 59 surgeons. Most of these surgeons (64%) operated on fewer than ten cases.

2.1.5 The picture is similar for many other cancers. The graphs below show that the majority of surgeons operating on patients with rectal cancer or kidney cancer performed fewer than six operations for these conditions over a one year period.

SURGICAL CANCER WORKLOAD (NI 1993-94)



SURGICAL CANCER WORKLOAD (NI 1993-94)



- 2.1.6 Patients with lung cancer are investigated and managed in most hospitals in Northern Ireland. Such patients are usually cared for by general physicians or by respiratory physicians whose special interest lies outside lung cancer. Surgical resection can be curative if carried out during the early stages of the disease. However, in many cases patients with symptoms suggestive of lung cancer are not being referred early enough to the appropriate clinicians. This has resulted in a comparatively low surgical resection rate for lung cancer patients in the province.
- 2.1.7 Leukaemia and other haematological malignancies are treated by haematologists. These doctors have already developed a pattern of care which is similar to that proposed by this report. Clear referral pathways exist between peripheral hospitals and the Belfast hospitals with children and younger patients who require more intensive treatment being referred centrally. Older patients who require less complex therapy are treated locally.
- 2.1.8 The diagnosis and continuing treatment of cancer is dependent on ready access to high quality diagnostic services, including specialised diagnostic imaging, endoscopy, histopathology, cytology and haematology. New sophisticated techniques for the diagnosis of cancer are being developed. These should be evaluated prior to their introduction to the service in Northern Ireland.
- 2.1.9 The regional oncology service at Belvoir Park Hospital has tended to provide a natural focus for the treatment of cancer. Belvoir Park is not an acute hospital. It is the only centre for the delivery of radiotherapy and it undertakes the bulk of chemotherapy treatment. Consultants from Belvoir Park undertake out-patient clinics in almost all acute hospitals, but because of the wide dispersion of services there is a limited and infrequent service to many sites. The service is coming under increasing pressure because of developments in cancer treatment and in particular the increasing use of radiotherapy and chemotherapy for both curative and palliative purposes. Many hospitals are demanding more oncology input than is available from existing resources. Professionals are increasingly recognising the benefits of shared clinics involving surgeons, oncologists and radiologists.

2.2 Palliative Care

- 2.2.1 Palliative care is acknowledged as an important and integral part of cancer care. It is an area which has undergone considerable development in recent years. The voluntary sector has played a very significant role in the development of this service. It is a key provider of palliative care services in the province, both in hospices and in the community. However, current provision is patchy and has developed in an unco-ordinated manner.
- 2.2.2 The Working Group considered that cancer services in Northern Ireland have in general been of a high quality, and at least comparable to services elsewhere in the United Kingdom. There is a high level of commitment from all those involved in providing the service and indications are that patients are satisfied with the services they receive. The Working Group considered that the necessary developments in cancer services to meet future demand should build upon the excellent foundations which already exist.

3. THE NEED FOR CHANGE

3.1 Access to High Quality Care

- 3.1.1 There is variation throughout the UK in the treatment of cancer. The current system of cancer care in Northern Ireland has provided, and continues to provide, high quality care for most patients. This is underlined by the considerable improvements in survival that have been achieved for a number of cancers over the past few decades. The improved outlook for children with leukaemia has already been mentioned. Impressive results have also been obtained in respect of other childhood cancers such as a type of kidney cancer known as Wilms tumour, as well as in a number of adult cancers e.g. testicular cancer.
- 3.1.2 Nevertheless, the sub-group reports show that not all patients receive the same standards of care. In the case of breast cancer it has been shown that there is wide variation across Northern Ireland in the way that services are delivered. For example, some patients are managed by breast care teams treating a considerable number of women with breast disease each year, while others are managed by general surgeons who are treating between one and four cases annually.
- 3.1.3 In relation to gynaecological cancers, there is evidence that the staging of some patients with cancer of the uterine body is less than adequate. This can result in sub-optimal treatment. Furthermore, it is estimated that up to 50% of women with ovarian cancer are managed in units with a workload which is too small to allow them to develop specialist expertise in cancer care.
- 3.1.4 The lung cancer sub-group have noted that more than 20% of patients in Northern Ireland do not receive specialist evaluation. In addition, considering the small number of patients given chemotherapy and the low rates of surgical intervention, they believed that some patients may not be receiving appropriate treatment.
- 3.1.5 All patients should have access to a uniformly high quality of care wherever they live. The Cancer Working Group is of the opinion that, if this is to occur the current system of care will need to change.

3.2 Benefits of Specialist Expertise and Teamwork

- 3.2.1 It seems reasonable to suppose that patients with cancer who are treated by cancer specialists, or in specialist cancer centres, would be treated more appropriately and thus have a better prospect of survival than similar patients treated by non-specialists. However, until fairly recently published evidence to support this view has not been available. This evidence has now been collated in a review which has been considered in detail by the Expert Advisory Group on Cancer (Selby P, Gillis C, Haward R, 1996). From the evidence it is clear that children with cancer and adults with rarer cancers, such as testicular cancer or soft tissue sarcoma, are more likely to be cured, when treated in specialist centres.
- 3.2.2 The evidence suggests that patients with moderately common cancers, eg of ovary, gullet, stomach, pancreas and those affecting the blood have better results when treated by specialists. They may have improved survival, a lower death rate during, or after, surgery or a shorter stay in hospital depending on the cancer in question.
- 3.2.3 In relation to the common cancers, the evidence again points to an advantage for the patient from specialist treatment. Patients with breast cancer who receive specialist care have been shown to benefit from less variability in the quality of

their care. They are more likely to be managed according to guidelines and to be entered into clinical trials. In addition, patients under specialist care often receive more appropriate chemotherapy and hormone therapy. These factors have been shown to be associated with improved quality and length of life. There is also evidence to show that surgeons who perform less than 30 operations for breast cancer each year have poorer outcomes than surgeons operating more frequently than this.

3.2.4 Patients with lung cancer, who are treated by specialist physicians, are more likely to have their diagnosis established. They have also been shown to have a survival advantage through entry into clinical trials. Surgical treatment for patients with colo-rectal cancer can be less than optimal when undertaken by non-specialists. Again the evidence suggests that specialist treatment of this condition can improve the outcome for the patient.

3.2.5 While most of the available evidence supports the contention that specialist cancer treatment is of advantage to patients, some studies have failed to show an advantage. However, there is no evidence that management by cancer specialists is associated with a poorer outcome. The Group was convinced that there is a strong clinical argument in favour of specialised cancer treatment for patients with the more common as well as the rarer cancers. It **recommended** that the management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.

3.2.6 Treatment by a specialist physician, surgeon or gynaecologist is only one facet of specialist care. Those specialising in cancer care usually see more patients with particular types of cancers than non-specialists, have access to a wider range of facilities, including support services, and work as members of a specialist team. It is clear that for many patients their quality of life and survival are crucially dependent upon being managed by a multidisciplinary, multiprofessional cancer team. Indeed the quality of the non-surgical treatment that patients receive can be as important as any surgical treatment they may have required.

3.2.7 High quality patient focused care will be best achieved through a collaborative effort involving a full multidisciplinary, multiprofessional team. Doctors, nurses, clinical pharmacists, physiotherapists, dietitians, speech and language therapists, diagnostic and therapeutic radiographers, occupational therapists and social workers will all have a part to play in the provision of a comprehensive cancer service. The provision of seamless care requires effective communication between health and social care professionals with expertise in cancer care.¹

3.2.8 The exact make-up of these cancer teams will vary depending upon the individual cancer but will usually include a non-surgical oncologist and cancer nurses. The Working Group **recommended** that all patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.

3.3 Advances in Chemotherapeutic Services

3.3.1 The use of cancer chemotherapy has grown considerably over the past 20 years. The predicted increase in the number of people with cancer (described in section 1.1.3), coupled with the expectation that current treatment regimens will be improved and novel drugs developed, means that the use of chemotherapy will

¹ A separate report entitled "A Framework for the Multiprofessional Contribution to Cancer Care in Northern Ireland" has been published. It addresses the multiprofessional contribution to cancer care in detail. Copies are available from the Department of Health and Social Services.

continue to expand for the foreseeable future. The increasing need for chemotherapy is already stretching local resources to the limit.

- 3.3.2 Chemotherapy offers a survival advantage to many patients with cancer. At present most cancer chemotherapy is delivered centrally in Belfast. For the more common cancers requiring less complicated treatment this is usually provided in outpatient clinics. This means that patients often have to travel a considerable distance, on a regular basis, to receive their treatment. It also means that there is limited scope for contact between doctors working in hospitals outside Belfast and the non-surgical oncologists who provide this treatment.

3.4 Nurses Caring for People with Cancer

- 3.4.1 Cancer nursing services should be structured so that patients have access to high quality care and treatment. Staffing levels will depend on the needs of patients but should consist of:

- qualified nurses with post-registration experience and education in cancer nursing;
- specialist nurses with specific expertise in, for example, breast care, stoma care, cancer chemotherapy, paediatric oncology, palliative care or community liaison;
- health care support workers.

Expert care requires nursing staff with experience in various treatment modalities. This will be achieved through provider units supporting a critical mass of patients. Experience will be gained in the care of common and rare forms of cancer.

- 3.4.2 Collaboration between all provider units is essential. The regional centre should be the “resource hub” for other provider units, primary care teams, palliative care teams and for voluntary organisations such as the hospice movement, Marie Curie Cancer Care and Cancer Relief Macmillan Fund. This will ensure a co-ordinated approach to patient care with uniformity of practice. It will also provide education and training for cancer nurses in promoting awareness and prevention of cancer, the treatment of patients with cancer and their rehabilitation.

3.5 Public Expectations

- 3.5.1 Cancer is an emotive subject. Already patients and their advocates have had an enormous impact upon the development of cancer services, particularly in relation to screening services. Patients’ expectations continue to rise. Individuals, community groups and the voluntary sector are rightly demanding the highest possible standard of cancer care. The Working Group was particularly impressed by “A Charter for People with Cancer” which has been produced by the Derry Well Women Cancer Support Group. This is reproduced as **Appendix 5**.
- 3.5.2 The two main advocacy groups for patients with cancer in Northern Ireland are the Ulster Cancer Foundation and Action Cancer. In their evidence to the Working Group, both identified the need for a more co-ordinated service, based upon specialists located in cancer units and cancer centres. They would both also welcome a closer working relationship between themselves and the statutory providers of cancer services.
- 3.5.3 In its report “A Review of Cancer Services in N. Ireland”, the Ulster Cancer Foundation stated that there is a need for:

- a team approach to all aspects of the patient's treatment and after care;
- expert oncology input from cancer centre to cancer unit;
- more patients to be entered into clinical trials, with closer integration between cancer research and clinical services;
- more curricular time to be allocated to issues associated with cancer treatment and care in undergraduate and postgraduate health professional education; and
- audit and outcome measurement.

The Foundation went on to say that there may be a need to see a smaller number of hospitals providing good quality care. It supported the establishment of a unified cancer centre located on a central acute teaching hospital site.

3.5.4 In its submission to the Working Group "Developing Cancer Services in Northern Ireland", Action Cancer stated that it welcomed any proposal that would result in a greater provision of quality care services for patients and their families. The charity has suggested the establishment of a Cancer Forum to co-ordinate cancer service delivery between the statutory and the voluntary sectors. Such a forum would:

- empower participant organisations;
- facilitate a team approach to cancer care;
- enable resources to be shared; and
- promote better communication.

The Working Group **recommended** that a Cancer Forum should be established involving all key interests in the delivery of cancer services.

3.6 Regional Strategy

3.6.1 The Regional Strategy for Health and Social Well-being (1997-2002) sets out a framework for the future direction of acute services. It points to the provision of highly complex and expensive specialised services tending to be provided at one centre serving the whole province. Other acute specialties will be concentrated onto fewer acute sites in order that there is a sufficient volume of work to sustain skills and also to ensure that expensive equipment is used intensively.

3.6.2 The Working Group considered that any future investment in specialist cancer services should follow closely the pattern of investment in other specialist acute services.

4. PROPOSALS FOR THE PROVISION OF CANCER SERVICES IN NORTHERN IRELAND

4.1 Guiding principles

4.1.1 The Working Group examined the present organisation of cancer services in Northern Ireland in the light of the EAGC report and the emerging evidence. The Working Group considers that there should be significant change to the organisation of cancer services. The guiding principles behind any change must include:

1. A patient-centred service.
2. Access to a uniformly high quality of care for all patients.
3. Increased specialisation in cancer management.
4. A multidisciplinary, multiprofessional team approach.
5. Services which are research-based and submitted to regular formalised outcome assessment.

4.1.2 In examining these principles against the structures recommended in the EAGC report the Working Group proposed three levels of care for Northern Ireland:

1. Primary care - this is seen as the focus for cancer care. The primary care team is seen not only as an important provider of continuing medical care but also as an advocate for the patient. The Working Group recognised the important role of the GP as a purchaser of secondary cancer care - either directly as a GP fundholder or indirectly by working with Boards as commissioners.
2. A number of cancer units each providing:
 - multidisciplinary, multiprofessional expertise for all common cancers occurring within their local catchment population;
 - a range of specialist diagnostic, therapeutic and support services, including radiography, endoscopy, chemotherapy for the more common cancers, and laboratory services;
 - intensive care and additional medical and surgical services.
3. A designated cancer centre providing:
 - multidisciplinary, multiprofessional expertise for all common cancers within its local catchment population (i.e. it will act as a cancer unit for this population);
 - regional expertise in all other cancers (except for some very rare cancers which will continue to be treated outside Northern Ireland);
 - specialist diagnostic services, including ready access to a full range of clinical imaging services;
 - specialist therapeutic services, including radiotherapy and complex chemotherapy;
 - a regional focus for research, audit, teaching and training.

4.2 Primary Care

- 4.2.1 Primary care teams have a central role in the long-term management and support of cancer patients and their families. Their ability to fulfil this role is dependent upon timely and appropriate communication with the hospital sector. In addition to the management of individual patients, primary care teams are responsible for some important public health functions eg cancer prevention, cancer screening and purchasing cancer services either as fundholders or locality commissioners.

Early diagnosis and referral

- 4.2.2 Local guidelines relating to the early diagnosis and referral of patients with cancer need to be developed. These should be based upon nationally agreed, evidence based standards which can be adopted unchanged or adapted, as necessary, for local use. A number of relevant nationally agreed guidelines already exist, although some may be relatively inaccessible to GPs.
- 4.2.3 General practitioners will need to know which particular cancer services are offered in each cancer unit, as well as in the cancer centre. In order to ensure appropriate referral and to minimise delay there would be merit in the production of a cancer directory. This could list the availability of multiprofessional, multidisciplinary site specific teams throughout the province. Team members could be named and contact telephone numbers listed. The proposed Standing Advisory Committee on Cancer Services could be responsible for its production and revision (see section 4.10.1).

Health promotion

- 4.2.4 It is known that certain cancers may be avoided and that more might be cured if detected earlier. Prevention of cancer involves raising public awareness of the relevant risk factors, encouraging people to change to a healthier lifestyle and creating an environment where it is possible for people to make healthy choices. It includes the availability of well organised screening services for breast and cervical cancer. Effective treatment is now possible for an increasing number of patients who develop the disease. Almost two-thirds of people diagnosed with cancer are cured or live with their cancer to die from other causes. The earlier cancer is detected the better. People should be encouraged to present early when they notice a change such as prolonged hoarseness or cough, a lump, abnormal bleeding or unexplained weight loss.
- 4.2.5 A significant reduction in preventable deaths from cancer will depend upon the degree to which primary care teams can assist their patients in avoiding risk factors for cancer, such as tobacco use, and support the national screening programmes for breast and cervical cancer. In this regard primary care practitioners should be familiar with the booklet "European Code Against Cancer: a tool for general practitioners", as well as the Department's action plan for cancer. The population should be encouraged and supported to follow the European ten point code against cancer which is reproduced at **Appendix 6**. There should be investment in cancer prevention initiatives now for future health gain.

Communication

- 4.2.6 Currently many general practitioners value the availability of local hospital doctors with whom they have developed a close working relationship and whom they can contact readily by telephone. The development of cancer units must not result in hospital based teams becoming remote and unresponsive to the needs of general practitioners. The provision of seamless care depends upon effective communication between the primary care team and the hospital based team. This

is a two way process and it is important that contact can be made between any member of either team. Good communication facilitates rapid patient referral and ensures appropriate community care and follow-up.

4.2.7

One of the problems faced by GPs caring for seriously ill patients in the community is a lack of timely information. The box below gives an example of the type of information GPs require when such patients are transferred from the hospital to the community. The use of a systematic format such as the one suggested will ensure that all important points are covered. The hospital team should make contact with the GP at least one day before the patient is discharged. It may not be appropriate to record some of the points set out below in a letter to which the patient would have access. The Group **recommended** that cancer units should, in conjunction with local GPs and other providers, develop an effective communication strategy. Purchasers will wish to ensure that such a strategy has been developed.

An example of the information requirements of GPs when a seriously ill patient is discharged from hospital to community care.

- clinical diagnosis
- prognosis
- objectives of treatment (curative or palliative)
- type of treatment (radiotherapy/ chemotherapy) and duration
- what the patient and relatives have been told about the illness and about the treatment
- how the patient and their family perceive the illness
- drugs and other treatments used and, if uncommon, their side-effects and treatment
- follow-up arrangements

4.3 Cancer Units

4.3.1 To improve the outcome of patients with cancer it is proposed that a number of cancer units should be established. These units should deal with the more common cancers arising in their catchment populations.

Increased specialisation

4.3.2 Each unit will have a team of consultants skilled in the management of disease in those organs in which the more common cancers occur, for example, the breast, colon and rectum. These clinicians will treat patients with both benign and malignant disease in these areas but must have a special interest in the treatment of cancer. In order to ensure stability and continuity of care each unit should be staffed by at least two consultants specialising in the management of each of the more common cancers. The Working Group recognised the need for complementarity in the range of specialties provided, for example, gynaecology, urology and colorectal surgery.

4.3.3 In future clinical training programmes will make it possible for purchasers and providers to recognise cancer specialists. Current consultants should be identified as having a specialist interest in cancer by their peers.

Multidisciplinary team approach

4.3.4 The treatment of cancer within cancer units should be based on a multiprofessional, multidisciplinary team approach. The membership of the team should include:

- surgeon/ physician/ gynaecologist
- oncologist
- haematologist
- specialist nurses
- clinical pharmacist
- radiologist
- pathologist
- palliative care physician

The inclusion of other team members will depend upon the needs of the individual patient.

4.3.5 The Working Group considered that non-surgical oncology should be an essential element of specialist expertise at cancer units. The regional oncology service based in the cancer centre will need to work closely with cancer units in order to ensure a balance between dedicated oncological support to units and the increasing need for sub-specialisation within oncology. It is likely that the service to each unit would be provided by more than two oncologists.

4.3.6 It is proposed that each cancer unit should provide chemotherapy services for the treatment of common cancers. These services will include out-patient, in-patient and day-care facilities, and should be supported by clinical pharmacists and nurses who are specialised in the provision of chemotherapy services. There should be appropriate facilities for the preparation of intra-venous cytotoxic agents, including biological safety cabinets (Joint Council for Clinical Oncology, 1994).

4.3.7 Cancer units will need to develop a comprehensive range of support services. Examples include:

- i. laboratory services - with, for example, histopathology and a tumour marker service
- ii. radiology services - with access to guided fine needle aspiration, intra-venous urography, mammography, ultrasound and CT/MRI scanning
- iii. anaesthetic services - including an on-site intensive care unit and a pain management service
- iv. counselling services - for patients and their families.

4.3.8 The cancer unit should work closely with primary care services, other service providers and with the cancer centre to ensure that there is proper integration of services. The Working Group considered that the appointment of a lead clinician as recommended by the EAGC will be a key element in guaranteeing the delivery of high quality services. The lead clinician will be responsible for ensuring:

- the full co-ordination and integration of cancer services;
- the development of formalised clinical audit both at a local level and within a regional framework;
- participation in research, especially clinical trials;
- the development and monitoring of guidelines and protocols; and
- the collection of accurate and timely data.

Cancers suitable for treatment in cancer units

4.3.9 The Working Group was of the opinion that the role of cancer units should be limited to the treatment of the more common cancers. The following cancers were identified as suitable for management in such units:

- breast;
- colo-rectal;
- lung (non-surgical treatment);
- ovary;
- body of uterus;
- most urological cancers; and
- chronic leukaemia.

The majority of patients with these cancers will be treated within a cancer unit. However, some patients with more complex disease may need to be treated in the cancer centre. The sub-group reports give further details on individual cancers. The Working Group considered that the above list of cancers should be kept under review in light of further advances in cancer therapy.

The number of cancer units

4.3.10 The Working Group gave careful consideration to the number of cancer units which would be required for the population of Northern Ireland. In determining the appropriate number of units the following factors were taken into account:

- the need to develop specialisation and multiprofessional, multidisciplinary team working;
- the need to ensure an adequate volume of work to maintain skills, support audit and research and provide services in a cost-effective manner;
- the recognition that some cancer services which are now available only in Belfast could be made more accessible.

4.3.11 The Working Group examined current referral patterns and determined the likely catchment populations for cancer services. Table 1 shows that the local catchment population for the regional cancer centre is likely to be around 530,000. The table also shows that hospitals within each Board would be required to serve a remaining population of between 253,000 and 270,000.

Table 1: Estimated catchment populations

	Catchment population	% of total population
Cancer Centre*	531,423	34
Eastern Board*	260,075	16
Northern Board	269,756	17
Southern Board	253,347	16
Western Board	263,234	17
Total	1,577,835	100

*Based on present referral patterns to the Belfast hospitals.

Table 2 shows the predicted numbers of new cancers occurring in such populations each year.

Table 2: Estimated annual incidence of specific cancers occurring within defined populations in Northern Ireland in 1997

Cancer	Number of new cases expected per year within a population of:-	
	260,000	530,000
Breast	110	227
Bladder	79	163
Colon	75	155
Kidney	19	39
Lung	183	377
Prostate	64	131
Rectal	23	48

In considering the various factors outlined above, the Working Group proposed that within each Board Area there should be one cancer unit. Each cancer unit would form the focus for the treatment of common cancers for its catchment population and would form an important link between primary care and the regional cancer centre.

4.3.12

The Working Group recommended that Northern Ireland should have one cancer centre, which in addition to its regional role, should act as a cancer unit to its local catchment population of around half a million. It further recommended that there should be four other cancer units, one in each Board area, each serving a population of around a quarter of a million.

4.4 The Cancer Centre

4.4.1 The Working Group considered the need for a regional specialised centre for cancer in Northern Ireland. It was recognised that much of the specialised regional work is already provided at the Belfast City Hospital and the Royal Group of Hospitals. The Acute Hospitals Reorganisation Project has set out working relationships which can form the basis for a regional cancer centre. It was considered that many essential elements already exist on these two sites for the development of a high quality cancer centre; examples include:

- specialised surgery;
- sophisticated diagnostic facilities;
- intensive care;
- expertise in rare cancers;
- medical support services; and
- an excellent academic and clinical research profile.

4.4.2 The Working Group considered that the proposals for a cancer centre as set out in the EAGC are an essential element in improving cancer services. The Working Group proposed that the Belfast City Hospital, working closely with the Royal Group of Hospitals, should be developed as the regional cancer centre for Northern Ireland.

4.5 Radiotherapy and Chemotherapy Services

4.5.1 Radiotherapy and chemotherapy play a central role in the curative and palliative treatment of cancer. These services are presently delivered mainly at the regional oncology centre in Belvoir Park Hospital. For many years this unit has delivered, and continues to deliver, high quality care to patients and rightly deserves the very great regard in which it is held by the people of Northern Ireland. It is also sited within a pleasant environment on the outskirts of Belfast and has developed its own ethos and strong sense of identity. However, the clinicians and other health professionals working in the regional oncology service recognise that the predictions of increasing workload and emerging new technologies are set to change radically the way in which their services need to be delivered. It is recognised already that the service is coming under considerable pressure and urgent steps need to be taken to ensure that patients' needs can continue to be met.

4.5.2 Changes in treatments, together with demographic trends in cancer incidence, will require clinicians to deal with patients who are likely to be more ill and to have complex medical problems. The effect of these trends is already beginning to be seen. It is clear that radiotherapy and chemotherapy in future will require to be delivered within an acute hospital setting where there is the full back-up of acute and diagnostic services. Such on-site services should include:

- intensive care facilities;
- laboratory services, including haematology and immunology;
- diagnostic imaging, including MRI scanning; and
- acute medical and surgical support.

Cancer services are concerned with the care of acutely ill patients for whom direct access, on site, to general and specialist physicians and surgeons is very desirable. Most cancer patients are older people who need access to a wide range of other expertise from a broad spectrum of health and social care staff.

4.5.3 Medical and clinical oncologists are an essential part of the multidisciplinary team approach to cancer care. The benefits from collaborative working would be

realised more fully if the regional oncology service was an integral part of the regional cancer centre. Such a move would also facilitate research and enable staff, both clinical and non-clinical, to train within the broad environment of general acute services, rather than working wholly within a specialist hospital. The Working Group **recommended** that radiotherapy services, together with chemotherapy services, should be moved as soon as possible to the Belfast City Hospital and become an integral part of the regional cancer centre.

4.5.4 During recent years there has been a gradual move towards the delivery of some chemotherapy in hospitals other than Belvoir Park. This means that for some patients relatively straightforward chemotherapy can be delivered closer to their own home. The Working Group welcomes this innovation as it can be seen to greatly benefit patients. Some patients have spoken of 12 hour round trips to Belvoir Park in order to receive a half-hour treatment.

4.5.5 The Working Group **recommended** that each cancer unit should develop a chemotherapy service. This service should be staffed by designated specialist nurses and pharmacists, and should be overseen by the non-surgical oncologist attached to the unit, with back-up from a haematologist. The chemotherapy service should be very closely linked to the regional cancer centre and should comply with quality control guidance.

4.5.6 The medical and clinical oncologists will have to provide a service to the four cancer units. It is unlikely that each cancer unit will require more than ten sessions of oncology input per week in the near future. This should be provided by two or more oncologists specialising in the management of the more common cancers. The Working Group was mindful of the difficulties which can arise when one specialist working alone provides a service. The Group believed that the regional oncology service should remain as a single entity providing a service to the cancer centre and the 4 cancer units.

Workforce in oncology

4.5.7 **Clinical oncologists** specialise in both radiotherapy and chemotherapy. Currently there are 8 consultant clinical oncologists in post. They are all based at Belvoir Park Hospital and provide an out-patient service to all acute hospitals in the province. These consultants are supported by a staff grade doctor and an associate specialist. In addition there are five doctors in training, all at registrar grade.

4.5.8 **Medical oncologists** specialise in chemotherapy. One consultant provides this service at present although a Professor of Oncology, who is a medical oncologist, has recently been appointed.

4.5.9 **Non-surgical oncologists** is the term used to describe practitioners in the two related disciplines of clinical and medical oncology. The Working Group considered the workforce requirements for one cancer centre linked to four cancer units. Based on guidance from the Royal College of Radiologists, the need to provide enough oncologists to allow sub-specialisation and the EAGC suggestion that a cancer unit should have a minimum of five oncology sessions per week, the Working Group **recommended** that there should be a minimum target of 13 consultants in non-surgical oncology for Northern Ireland by 2005. This is the minimum number of consultants that will be required to provide a service to patients. It takes no account of the need for additional consultant input into training and research. Therefore the target will need to be kept under review by the Specialty Advisory Committee on Non-surgical Oncology, as will training requirements for the specialty.

4.6 Making the Best Use of Existing Expertise

4.6.1 The Working Group recognised that the proposal to establish four cancer units will have significant resource implications. In particular it is not likely that any Area General Hospital in Northern Ireland would at present have the staffing or resources to become established as a cancer unit. In addition the Working Group recognised that whilst Northern Ireland has a number of highly trained consultants and other health professionals who have a special interest and a highly creditable expertise in certain cancers, these staff are widely dispersed throughout the service. The Working Group considered that purchasers will need to work closely with providers in order to ensure that this valuable resource is not wasted and is used to its fullest potential. The present configuration of Trusts may, in some instances, provide a challenge to this objective, but this should be overcome in the interests of delivering a high quality cancer service to patients. Trusts will need to work collaboratively in order to ensure that Trust boundaries do not prevent the establishment of specialist cancer teams. There are already some good examples of effective working arrangements between Trusts, such as joint appointments and visiting consultants, and the Working Group considered that such arrangements should be encouraged in order to make use of available expertise and to strengthen professional links between hospitals.

4.6.2 The centre may require input from clinicians based mainly in other Belfast hospitals who currently provide a regional service for patients with specific types of cancer. Innovative contractual arrangements will be required in the short to medium term. The Group **recommended** that any new appointments of trained cancer specialists should be to cancer units or to the cancer centre. This will have an impact upon training requirements as doctors will need to be trained for specific posts within units or the centre.

4.7 The Role of Other Acute Hospitals

4.7.1 It was acknowledged that the establishment of cancer units and a cancer centre will result in a change in the workload at remaining acute hospitals. The development of specialised cancer services will allow general practitioners to refer patients with symptoms and signs suggestive of cancer directly to cancer units or the cancer centre. However, a number of patients who turn out to have cancer will present to their GPs with non-specific complaints. Thus a significant number of patients with cancer will continue to be diagnosed at other acute hospitals. In addition some patients with cancer will present to non-cancer unit hospitals as emergencies requiring immediate treatment.

4.7.2 The Working Group **recommended** that guidelines should be drawn up and agreed for the appropriate investigation and management of patients presenting to non-cancer unit hospitals who turn out to have cancer. The lead clinician in the cancer unit will be responsible for liaising with clinicians in other acute hospitals, drawing up agreed guidelines and ensuring regular clinical audit.

4.8 Palliative Care

4.8.1 Palliative care is the active, total care of patients and their families by a multiprofessional team when the patient's disease is no longer responsive to curative treatment. Palliative care services may be provided in community and inpatient settings by the Hospital and Personal Social Services or by the voluntary sector or in partnership with each other.

4.8.2 The aim must be the co-ordinated provision of an appropriate level of patient

focused and seamless care through all stages of an individual's illness, to cure or death and into family bereavement. The level of care required will depend on the needs of the patient and carers. In both the community and hospital based setting three levels of care can be identified:

- primary level - delivered by the primary care/ ward team;
- secondary level - requiring some specialist intervention e.g. community palliative care team/ hospital palliative care team; and
- tertiary care - requiring the input of specialist palliative care services.

4.8.3 The criteria for specialist palliative care services are defined by the National Council for Hospice and Palliative Care Services. The Working Group **recommended** that the cancer centre and cancer units should each develop a specialist multiprofessional palliative care team. All providers of palliative care services must participate in on-going audit, research and education. They should be able to communicate effectively with all those involved in the care of individual patients.

4.8.4 The Working Group **recommended** that there should be a comprehensive review of palliative care services in Northern Ireland. This review should undertake an assessment of the need for palliative care and should advise on how that need should be met.

4.9 Northern Ireland Cancer Registry

4.9.1 One of the problems encountered by the Cancer Working Group and a number of its sub-groups was the lack of information on patients with cancer in Northern Ireland. This is a serious disadvantage for those planning and purchasing cancer services. It also makes it difficult to monitor survival, to audit the service and to carry out research. In order to overcome this problem a new Northern Ireland Cancer Registry was established in 1994. At present it can only provide information about cancer deaths and has recently published a report on this subject.

4.9.2 From 1996 the Registry will be in a position to collect incident data (i.e. information on the number of new patients who develop cancer each year) as well as information on the number of patients being admitted to hospital for cancer treatment. However, despite being funded to collect such data the Registry does not have sufficient resources to enable appropriate analysis and dissemination of these data. Currently over 30% of the Registry's running costs are met by charitable donations from the Ulster Cancer Foundation. The Group **recommended** that the Northern Ireland Cancer Registry should be adequately resourced.

4.9.3 The Working Group recognised the value and importance of other specific registries which have been developed locally i.e. the colorectal cancer registry and the malignant melanoma registry. These registries need to develop their links with the Northern Ireland Cancer Registry. Any new specialist registries should only be developed in collaboration with the Northern Ireland Cancer Registry.

4.10 Advisory Committees on Cancer

4.10.1 The Working Group was of the opinion that there was a need for a Standing Advisory Committee on Cancer Services to advise the Department on future

service developments and quality standards in the treatment of cancer. Its main function would be to advise on the implementation of the recommendations of this report. Its remit would include:

- monitoring cancer services;
- development of guidelines and protocols;
- co-ordinating and facilitating audit and research;
- advising on future developments;
- advising on training standards; and
- producing an annual report.

- 4.10.2 Health and Social Services Boards should establish Cancer Commissioning Groups to oversee the local implementation of policy on the prevention and treatment of cancer. These groups would provide a focus for the development of local policies and guidelines and would advise Boards and GP Fundholders. They should develop strong links with local voluntary and community groups. In addition, the Cancer Commissioning Groups should have a close working relationship with the Standing Advisory Committee on Cancer Services. This could be effected by inclusion of their chairman on the Standing Committee.

4.11 Audit

- 4.11.1 An ongoing programme of audit will be essential to test the objectives of improved outcomes and better standards of care for cancer patients. Audit activity will require to be comprehensive and detailed and will involve both medical and clinical audit to embrace the range of services provided by the cancer centre and the cancer units. Services within each location should be audited for the purpose of testing outcomes and quality of care, to produce useful comparative audit data between the cancer centre and cancer units. For this to happen there will need to be a regional audit framework which can be applied on a standard basis to enable such comparisons to be made. Cancer audit should also take note of national standards and objectives. Additionally, there may be a requirement to address specific audit topics at the request of the Department, the proposed Standing Advisory Committee on Cancer or the Regional Medical or Multiprofessional Audit Committees.

- 4.11.2 The nominated lead clinician in each location will have the responsibility of co-ordinating the audit effort and will produce an annual report of both medical and clinical audit work. Copies of the report should be submitted to the above committees and will feature in the annual submissions from each of those groups to the Department.

5. SUMMARY OF RECOMMENDATIONS

5.1 Recommendations

5.1.1. This report is concerned with the development of cancer services in Northern Ireland. Its primary objective is to ensure that patients with cancer receive uniformly high quality care. Recent evidence has shown that patients have a better prospect of cure and a better quality of life if they are treated by cancer specialists working within a multidisciplinary, multiprofessional team. The Working Group believed that its proposals would not only improve the care of patients using current techniques but would also allow future advances in treatment to be applied rapidly. It recommended that:

1. The management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.
2. All patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.
3. A Cancer Forum should be established involving all key interests in the delivery of cancer services.
4. Cancer units should, in conjunction with local GPs and other providers, develop an effective communication strategy.
5. Northern Ireland should have one cancer centre, which in addition to its regional role, should act as a cancer unit to its local catchment population of around half a million.
6. There should be four other cancer units, one in each Board area, each serving a population of around a quarter of a million.
7. Radiotherapy services, together with chemotherapy services, should be moved as soon as possible to the Belfast City Hospital and become an integral part of the regional cancer centre.
8. Each cancer unit should develop a chemotherapy service. This service should be staffed by designated specialist nurses and pharmacists, and should be overseen by the non-surgical oncologist attached to the unit, with back-up from a haematologist.
9. There should be a minimum target of 13 consultants in non-surgical oncology for Northern Ireland by 2005.
10. Any new appointments of trained cancer specialists should be to cancer units or to the cancer centre.
11. Guidelines should be drawn up and agreed for the appropriate investigation and management of patients presenting to non-cancer unit hospitals who turn out to have cancer.
12. The cancer centre and cancer units should each develop a specialist multiprofessional palliative care team.
13. There should be a comprehensive review of palliative care services in Northern Ireland.
14. The Northern Ireland Cancer Registry should be adequately resourced.

Appendix 1

MEMBERSHIP OF CANCER WORKING GROUP

Members were chosen for their potential contribution as individuals and not as representatives of particular interests.

Chairman

Dr Henrietta Campbell, Chief Medical Officer, Department of Health and Social Services

Membership

Mrs Rita Beattie, Nursing Director, Northern Ireland Hospice
Dr Anna Gavin, Director, Northern Ireland Cancer Registry
Dr Clifford Hall, Deputy Chief Medical Officer, Department of Health and Social Services
Dr Russell Houston, Clinical Oncologist, Northern Ireland Radiotherapy Centre, Belvoir Park Hospital
Mr George Humphries, Consultant Surgeon, Antrim Hospital
Dr Harold Jefferson, General Practitioner, Lisburn Health Centre
Dr Frank Kee, Consultant in Public Health Medicine, Northern Health and Social Services Board
Dr Don Keegan, Consultant Physician, Altnagelvin Area Hospital
Dr Bill McConnell, Director of Public Health, Western Health and Social Services Board
Dr James McKenna, Executive Chairman, Acute Hospitals Reorganisation Project
Dr Curly Morris, Consultant Haematologist, Belfast City Hospital
Professor Brian Rowlands, Professor of Surgery, The Queen's University of Belfast
Mrs Joan Thompson, Nursing Officer, Department of Health and Social Services

Secretariat

Dr Adrian Mairs, Medical Officer, Department of Health and Social Services
Mrs Rosemary Scott, Secondary Care Branch, Department of Health and Social Services

Appendix 2

“A POLICY FRAMEWORK FOR COMMISSIONING CANCER SERVICES” REPORT BY THE EXPERT ADVISORY GROUP ON CANCER TO THE CHIEF MEDICAL OFFICERS OF ENGLAND AND WALES

GENERAL PRINCIPLES

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, psychological aspects of cancer care should be considered at all stages.
- vii. Cancer registration and careful monitoring of treatment and outcomes are essential.

SUMMARY OF RECOMMENDATIONS

- 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.
- 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.
- 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.

- v. Cancer Units should appoint a lead clinician to co-ordinate services for cancer patients in a Unit. The lead clinician should be closely involved in negotiating service agreements with purchasers.
- vi. Professional bodies should urgently develop guidance on the level of expertise and support required to manage the commoner cancers.
- vii. The Health Departments should work with professional bodies in developing the role of Primary Health Care Teams in the management of cancer.
- 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.
- ix. There are manpower implications for all specialties and professions involved in cancer care. Discussions should be held with appropriate professional bodies.
- x. Radiotherapy should normally be provided in a Cancer Centre. In exceptional 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.
- 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 be involved.
- xii. Education, audit, research into cancer care and the entry of patients into trials are important parts of the programme.
- 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 Expert Advisory Group on Cancer should in association with the NHS Executive and the Welsh Office Health Department monitor the implementation of these recommendations and report regularly to Ministers.

Appendix 3

ORGANISATIONS AND INDIVIDUALS WHO PROVIDED EVIDENCE TO THE CANCER WORKING GROUP

Action Cancer
Derry Well Woman Centre
Ulster Cancer Foundation
Patrick Johnston, Senior Investigator, National Cancer Institute, US Department of Health
and Human Services, Public Health Service National Institutes of Health, Maryland
The General Practitioners, Coleraine Health Centre
The General Practitioners, Ballymoney Health Centre
Mr E Fee, Director of Acute Hospital Services, Sperrin Lakeland Management Unit,
Units Administration, Tyrone County Hospital
Mrs H Boyd, Chief Executive, Green Park Healthcare Trust
Dr S D Nelson, Consultant Haematologist, Craigavon Area Hospital Group HSS Trust
Mr F J Mullan, Consultant Surgeon, Coleraine Hospital
Mr T Fannin, Consultant Neuro-surgeon, Royal Victoria Hospital
Dr C Russell, Consultant Surgeon, Royal Victoria Hospital
Mr R A J Spence, Consultant Surgeon, Belfast City Hospital
Dr E N Shannon, Chairman, North East Ulster Subdivision, British Medical Association
Dr D G Sinnamon, Consultant Physician, Coleraine Hospital
The Cancer Chemotherapy Team, Coleraine Hospital
Dr B C Bonnar, Mountsandel Surgery, Coleraine
Down Lisburn HSS Trust
Green Park HSS Trust
Altnagelvin Group of Hospitals
Newry and Mourne HSS Trust
Craigavon Area Hospital Group HSS Trust
Mater Infirmorum Hospital HSS Trust
The Ulster, North Down and Ards Hospitals HSS Trust
Causeway HSS Trust
United Hospitals Group
Sperrin Lakeland Management Unit
Armagh Dungannon HSS Trust

Appendix 4

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Appendix 5

LIVING WITH CANCER

A CHARTER FOR PEOPLE WITH CANCER

Introduction

This charter is being presented by us from our own experiences both good and bad, in the hope that it will bring a greater awareness to the health care professions of the fears and anxieties of people diagnosed with cancer, that they in turn will be treated with the respect and sensitivity they deserve.

Cancer Support Group
Derry Well Woman

The Charter is in eight points:-

1. Diagnosis.
2. Information.
3. Staff Training.
4. Physical Changes.
5. Chemotherapy.
6. Emotional Support/Counselling.
7. Life-Style.
8. Terminal Care.

Diagnosis

While respecting the professional judgement of the clinician and the individual's wishes, people receiving a cancer diagnosis have a right to:

- (a) be given their diagnosis by a member of staff in a caring and sensitive way;
- (b) be given their diagnosis in privacy with an opportunity to discuss the implications of the diagnosis. The diagnosis should not be given during a routine ward round;
- (c) have personal or professional support during and after they have been informed of their diagnosis and have access to a private area in which to discuss their diagnosis with family members;
- (d) be given their diagnosis personally, not by letter or telephone.

Information

People who have cancer have a right to information, both verbal and written:

- (a) on cancer in general and their own in particular; and
- (b) on treatments, their effects and side effects.

Staff Training

People who have cancer have the right to receive their care from staff who have received basic and on-going training in the field of cancer and its effects.

Physical Changes

No person should be expected to leave hospital until they have had the opportunity to discuss physical changes which they may have experienced. Where following up care of wounds is requested or required, the appropriate arrangements will be made, by ward staff, for community nursing staff to visit the patient at home. The person also has the right to:

- (a) be shown their wound;
- (b) be given information on care of their wound including appropriate clothing and washing; and
- (c) be told honestly of the possibility of baldness and the availability of wigs, etc.

Chemotherapy

People who are receiving chemotherapy have a right to:

- (a) receive this treatment in comfortable surroundings;
- (b) receive this treatment from a team of staff who have received relevant education and training and are sensitive to their needs; and
- (c) begin treatment within 30 minutes of the appointed time. Be given explanations in the event of delays in beginning or completing treatment.

Emotional Support/Counselling

People who have cancer have a right to emotional support for a period of at least 12 months after their diagnosis. This includes the right to:

- (a) at least 2 home visits by an appropriate health professional; and
- (b) information on local support services including cancer counselling service.

Life-Style

People who have cancer have the right to receive care in a non-judgemental way, regardless of their life-style, with emphasis on the future rather than the past. They have the right to:

- (a) support in the community for changes in their life-style which they may wish to make, eg stopping smoking, change in diet;
- (b) receive health promotional literature which is helpful, positive and non-judgemental; and

- (c) receive sound information on the range of therapies and treatments which they may wish to use in dealing with their cancer.

Terminal Care

Those who unfortunately require terminal care have the right to appropriate support in their usual residence.

- (a) if so requested, to be placed in contact with the Foyle Hospice;
- (b) access to hospital care as required for treatment and care which can no longer be provided in the community; and
- (c) the right to die at home with professional support for their family carers.

Appendix 6

EUROPEAN CODE AGAINST CANCER

Certain cancers may be avoided and general health improved if you adopt a healthier lifestyle

1. Do not smoke. Smokers, stop as quickly as possible and do not smoke in the presence of others. If you do not smoke, do not try it.
2. If you drink alcohol, whether beer, wine or spirits, moderate your consumption.
3. Increase your daily intake of vegetables and fresh fruit. Eat cereals with a high fibre content frequently.
4. Avoid becoming overweight, increase physical activity and limit intake of fatty foods.
5. Avoid excessive exposure to the sun and avoid sunburn especially in children.
6. Apply strictly regulations aimed at preventing any exposure to known cancer-causing substances. Follow all health and safety instructions on substances which may cause cancer.

More cancers may be cured if detected early

7. See your doctor if you notice a lump, a sore which does not heal (including in the mouth), a mole which changes in shape, size or colour, or any abnormal bleeding.
8. See your doctor if you have persistent problems, such as a persistent cough, persistent hoarseness, a change in bowel or urinary habits or an unexplained weight loss.

For women

9. Have a cervical smear regularly. Participate in organised screening programmes for cervical cancer.
10. Check your breasts regularly. Participate in organised mammographic screening programmes if you are over 50.

May 1996



Department of Health and Social Services