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1 Executive Summary

1 An All Wales service for cancer patients should be integrated at Cancer Centre level, with Cancer Centre services provided at three locations in Wales.

2 These locations will be Ysbyty Glan Clwyd NHS Trust in North Wales in association with Cancer Centres in England and Swansea and Velindre NHS Trusts in South Wales in association with their local acute general hospitals.

3 The All Wales dimension of an integrated comprehensive cancer service will be achieved by the adoption of common guidelines, protocols and audit operating between the three Centres in Wales. Common pathways for training and education will need to be developed across Wales to reinforce this concept for all professional staff involved in the delivery of cancer care to patients, their carers and families. This will be a considerable contribution to Clinical Effectiveness.

4 A cancer unit in Wales will equate to an acute general hospital which has a multidisciplinary team for a specific tumour site, be able to demonstrate effective integration of primary and secondary care and provide appropriate rapid access diagnostic services and referral routes to clearly identified specialist services.

5 Whilst specific expertise for the treatment of cancers is present in many locations, the development and organisation of multidisciplinary teams must maximise patient access to comprehensive specialist cancer care. Common treatment guidelines and protocols within Wales will help achieve this objective. Health Authorities in Wales will need to drive this process in order to deliver integrated services for patients.

6 Children should be treated in specific Children’s Cancer Centres, in the context of national clinical trials. The United Kingdom Children’s Cancer Study Group provide such a network and a majority of Welsh children are treated in Cardiff and Liverpool.

7 Information systems with the ability to collect common data must be used across all Trusts in Wales and feed the Wales Cancer Registry.

8 General Practitioners and Patients are often unaware as to where specialist cancer services are available. The lack of information needs to be addressed by all providers of cancer services.

9 Patients with cancer receiving care in Community Hospitals should have access to the full range of specialist services as required, provided to the standards outlined in this Report. Patients in Mid Wales, who have their treatment in England, must expect the same high standards to apply.

10 Tumour site specific professional groups developed from CSEG Task Groups should be retained at an All Wales level. These groups, together with the CSEG Project Office and the Wales Cancer Registry, could have a key role in monitoring outcome, updating guidance, providing feedback and impartial independent advice to Health Authorities, NHS Trusts and Primary Health Care Teams. This will need to be considered by Health Authorities.

11 This Report details key principles which should govern future care of cancer patients. Recommendations are made to achieve a high quality service for common cancers. These should be adopted by Health Authorities when commissioning cancer services.
2 The Cancer Services Expert Group

Introduction

2.1 DGM(95)64 announced the Government’s acceptance of the recommendations made by the Expert Advisory Group on Cancer established by the Chief Medical Officers of England and Wales. This report was published in April 1995. In 1995, The Secretary of State for Wales established a Cancer Services Expert Group (CSEG), to work with Health Authorities in Wales to identify how future cancer services should be configured. The remit of CSEG was:

• To advise the Welsh Office and identify for Health Authorities in Wales how the recommendations of the policy framework for commissioning cancer services can achieve:
  (i) access for the whole population to uniformly high quality care whilst
  (ii) respecting the principle of informed patient choice and taking account of local opinion and
  (iii) improve clinical and cost effectiveness aligned with maximum achievable cure rates, survival rates and quality of life.

• To ensure that any reorganisation or development of existing services takes the advice of patients’, families’ and carers’ views and preferences as well as the professionals involved in cancer care.

• To advise on the timescale for implementation and any implications for training, education and manpower within a framework of resource neutrality. To take account of any compensatory savings that might emerge consequent upon the rearrangement of existing services.

• To provide an initial report within 12 months.

• To inform purchasing intentions for cancer services in 1997/98.

Methodology

2.2 The CSEG strategy consists of two phases. The first phase, summarised in Figure 1, was concerned with a review of the current cancer service and a description of the ideal high quality service. Phase two will involve detailed working with Health Authorities to implement the recommendations.

2.3 This report, which is in two volumes, details phase one. The individual CSEG tumour site specific and generalist Task Group Reports are bound in Volume 2.

2.4 Centrally held information regarding cancer services in Wales was found to be incomplete. To remedy this deficiency, information via a proforma and site visit, was obtained directly from each acute general hospital or Trust in Wales having a responsibility for treating cancer patients.
2.5 Task Groups were set up as shown in Figure 2. Terms of reference are attached in Appendix 1. Members of the CSEG (Appendix 2) contributed as individuals and not as representatives of specific bodies or organisations. Each CSEG member was nominated as a Task Group leader. They were to liaise widely with colleagues and describe how the ideal service should be configured to provide the best care throughout the patient ‘journey’. This process involved a combination of telephone interviews, visits and the use of questionnaires together with literature review and input from specialist groups. Volume 2 contains details of the individual methodology and results of the Task Groups. Six focus groups were organised by Community Health Councils in Wales to ensure that a wide range of patient opinion contributed to the discussions of CSEG.

2.6 To provide feedback and to enable further dialogue within the NHS in Wales, a draft of Volume 1 of the CSEG Report was circulated to the NHS in Wales, Statutory Advisory and Professional Committees.

2.7 The CSEG Report is the result of a great deal of co-operation, enthusiasm and hard work of many individuals in the NHS in Wales - in particular the Task Group leaders and their colleagues who have made time to comment on individual reports that underpin the recommendations. We acknowledge their contribution and have included a list of individuals and groups in Appendix 2.
Figure 2
CSEG Task Groups

Skin/Head & Neck
- D. Patton

Gynaecological
- A. Evans; M. Adams

Gastrointestinal
- J. Stamatakis

Lung
- N. Stuart

Childhood
- D. Webb

Urological
- J. Williams

Haematological
- A. Burnett

Breast
- E. Roberts

GP/Primary Health Care Team
- S. Small; H. Marsh

The Patient View
- T. Bevan

Palliative Care & Quality of Life
- T. Finlay

Nursing
- A. Davies; S. Gregory

Prevention and Screening
- R. Halls

Diagnostics
- R. Denholm; P. Stamper

Information Issues
- J. Williams

Finance
- A. Almes
3 Cancer in Wales

Epidemiology

3.01 The pie chart, in Figure 3, shows the average annual registration of cancers in Wales during 1984-1988, for all ages, for the sites studied in this Report. Overall, 15,112 cancers were registered during this time. The most common (25%) being the gastrointestinal group of cancers (ICD 9 codes 150-157). The ICD 9 codes used to obtain these and other data are detailed in Appendix 3. Data from the Wales Cancer Registry, for the period 1979 to 1989, have been used to estimate the numbers of cancers expected for the year 2000. These are included in Section 4 (paragraphs 4.130-4.145) for each of the tumour sites studied.

3.02 With the exception of leukaemia and childhood cancers, there are no centrally held data relating to survival of cancer patients in Wales. Survival data have been reported by the West Midlands Regional Cancer Registry and these are included, in Section 4, for each of the tumour sites studied.

3.03 Cancers are responsible for about a quarter of all deaths (Figure 4).

3.04 Death from cancer is more common with increasing age (Figure 5). Cancers are responsible for a higher proportion of all causes of death among older age groups. For example, 41% of all deaths in the 55-64 age group are due to cancer. In comparison, cancers are a less common cause of death among younger people with only 7.5% of all deaths below 35 years of age.

3.05 Gastrointestinal and lung cancers account for over 50% of all cancer deaths (Figure 6). Further detail of years of life lost (YLL), for deaths under age 70, is included in Section 4 for each of the tumour sites studied.
3.06 In children, ICD codes are less appropriate. Cancers of the blood, central nervous system, neuroblastoma, Wilms’ tumour and soft tissue sarcoma are the most common (Figure 7). Diagnoses coded ‘endocrine’ and ‘head and neck’ are presumed to be neuroblastoma, Wilms’ tumour and some soft tissues sarcomas respectively.

3.07 Figures 7-10 show the changing patterns in mortality due to age and cancer site.

3.08 Cancer incidence increases with age (Figure 5). In 1981 6% of the population in Wales were aged 75 and over (Figure 11). This has risen to 7.8% in 1996 and is expected to reach 8.2% or 240,500 people by the year 2000.

3.09 This background of a rising incidence in cancer due to an ageing population is important and means there will be increasing demands for cancer services. Effective cancer treatments leading to increased cure rates will reap rewards in both social and financial terms. Morbidity data highlights the fact that cancer is essentially a disease of the elderly. However, the social costs of early death to carers and their families should not be forgotten.

Lowering the risks

3.10 Many cancers can be detected early and subsequently respond well to treatment with improved survival for example cancer of the breast. Some cancers, particularly cancer of the lung, are both difficult to detect at an early stage and difficult to treat once diagnosed. Other malignancies may be prevented by detection and treatment at a pre-cancerous stage e.g. cervical intra epithelial neoplasia (CIN).
Recommendations for Prevention

3.11 Within the field of health promotion, cancer prevention should be recognised as a priority. The European Union (EU) 10 point Cancer Code should be supported.

3.12 It will be important, in co-ordinating the major aspects of cancer prevention on an All Wales basis, to bring together relevant public health activities of Health Authorities and other agencies. Mechanisms will need to be developed to ensure effective integration of national with local activities.

3.13 There is a continuing need for Primary Health Care Teams (PHCTs) to provide an integrated service of cancer prevention, early diagnosis, and co-ordination of the management of patients with cancer.

3.14 General Practitioners should set priorities for advice on cancer prevention. High risk patients should be identified and advised appropriately.

Recommendations for Screening

3.15 Individuals need to be very clear as to what screening programmes offer and that screening is not prevention.

3.16 Screening programmes should only be undertaken on the basis of research evidence and where effective treatments are available.

3.17 The revenue consequences of screening aimed at the early detection of cancer and subsequent treatment costs must be agreed with commissioners prior to embarking on a screening programme.

3.18 Targeted screening for cancer families and genetic testing should be considered as part of the general services for the particular speciality, not as a population screen.
4 CSEG Findings

The Baseline

Introduction

4.001 The following brief overview is taken from the CSEG service review (The Baseline, Volume 2). It is based upon information obtained directly from Health Authorities and Trusts providing cancer services in Wales. Findings which relate to the management of the common cancers are also included alongside CSEG recommendations (paragraphs 4.050-4.110).

Local initiatives

4.002 Most Health Authorities and hospitals in Wales have recently reviewed their cancer services. This has resulted in a number of local initiatives. For example, there are two initiatives directed at improving communication. Firstly, in Morgannwg Health, the role of ‘key workers’ to link between primary and secondary hospital-based care is being evaluated and secondly, Velindre NHS Trust have developed and are using a patient-held record. In North Wales, with the proposed development of radiotherapy facilities at Ysbyty Glan Clwyd, a Cancer Strategy Group has been active for some time. In both South East and South West Wales, tumour site-specific groups have been set up and, in some cases, have already produced guidelines for the management of certain of the common cancers. The result of this activity is a general increased awareness of cancer services. An impetus exists which needs to be supported and directed to achieve the desired goal of an improved service for patients.

The patient view of cancer services

See also The Baseline & The Patient View Task Group Report, Volume 2

4.003 The patient focus groups highly rated the screening service provided by Breast Test Wales.

4.004 Communication between patients and professionals is poor. The patient focus groups revealed that there were many instances, in different parts of Wales, of patients being told their diagnosis and prognosis in open wards and corridors.

4.005 Patients and General Practitioners lack up-to-date information on where consultant led specialist cancer services are available and who provides the service.

Travel

4.006 There is a tension in providing highly specialised cancer services whilst also supporting patients’ choice and their travel expectations. To investigate this further, focus groups were specifically asked their views on travel. Members of all groups agreed they would travel any distance for diagnostic and surgical treatment if they knew they were going to ‘the best place’ that is, acknowledged for expertise and excellence.

4.007 A journey of 30 minutes to the General Practitioner or hospital was considered acceptable for routine follow up. For those undergoing debilitating treatment, journeys should be kept to within an hour and should be appropriate for the patients’ condition. The view was expressed that chemotherapy should, where possible, be given locally. As a result of these views on travel, geographical mapping was commissioned for each acute hospital in Wales. The map (Figure 12) is based on Ysbyty Glan Clwyd, Swansea and Velindre NHS Trusts and shows the 30 and 60 minute zones for travel by car. Similar maps for each acute Trust in Wales are included in Volume 2 (The Baseline).
‘It is a myth that everyone has the use of a car’ was one of the comments made at a focus group and is associated with concerns over the costs incurred in travelling. Many Anglesey patients, facing a journey of at least an hour and a half to Clatterbridge, praised the charity that organised a minibus to take patients from ‘door to door’.

Ambulance services provide emergency (EMS) and patient (PTS) transport services. PTS also includes transport by car. There were some instances where changes made at hospital level failed to take account of implications on transport services. All ambulance services stated that they were aware of the needs for flexibility in transport arrangements for cancer patients. Some considered that they could further contribute to the services provided in primary care, particularly in out-of-hours time.

The General Practitioner view of cancer services

See also The Baseline & GP/PHCT Task Group Reports, Volume 2

The General Practitioner questionnaire, subsequently referred to as the GP survey, corroborated the patients view that Breast Test Wales provided a highly rated service.

Diagnostic and treatment services for haematological malignancies, although relatively rare in general practice, were also considered to be good.

Paediatric cancers are rare in general practice, but the services were generally highly rated by those who had experience of them.

Access to urology, ENT and dermatology was most difficult but, when access was achieved, there was less concern about overall quality of these services.

Forty-two percent of those answering the GP survey felt that access to palliative care in-patient services was inadequate or grossly inadequate. Quality of service, when access was achieved, was generally fairly well rated.

Hospital services

See also The Baseline - Hospital-based cancer care, and Task Group Reports, Volume 2

Arrangements for rapid access diagnostic services were commended in the GP survey.

All acute hospitals in Wales treat patients with cancer. There are widely differing arrangements for the provision of chemotherapy. For example, chemotherapy for lung cancer is provided locally by either a respiratory physician, haematologist (at the request of the respiratory physician), visiting clinical oncologist, medical oncologist or at the radiotherapy centre with the patients travelling to receive treatment.

Radiotherapy, for patients in North Wales, is currently provided by the Clatterbridge Centre for Oncology and the Christie Hospital in Manchester covering 70% and 30% respectively. This referral pattern will change when the new radiotherapy facilities planned for Ysbyty Glan Clwyd are functional.

In South Wales, radiotherapy is provided at Velindre and Singleton hospitals which also provide extensive oncology outreach clinics. There is an operational superficial X-ray machine at West Wales General Hospital.

The majority of cancer patients living in Mid Wales travel to neighbouring Welsh and English hospitals for their treatment. A number of outpatient clinics are held in the Community Hospitals with visiting consultants from these hospitals.

Fifteen Trusts, providing cancer services, have designated a lead clinician for cancer. Proforma responses indicate that lead clinicians have various responsibilities including for example, overseeing clinical protocol development, clinical audit, staff training, research, service development and liaising with colleagues, General Practitioners and Health Authorities.
Local treatment guidelines and protocols are being developed and are generally welcomed as the basis for the future management of cancer patients. However, there is no mechanism for ensuring that common protocols, based on best available evidence of outcome, are adopted.

**Workforce**

*See The Baseline - Workforce, Volume 2*

Changes in health care are currently causing polarisation between the need for specialisation of skills and equipment at one end and community based generic services at the other. Parallel to this is the perception of patients, families and carers that only specialists will give the right advice. This requirement for specialist care is identified in the Nursing and Patient View Task Group Reports.

There appears to be a high number of cancer patients nursed in non-specialist areas as well as specialist areas (see Nursing Task Group Report). There are a lack of computerised workforce systems and it is difficult to provide details of ratio of nurses to cancer patients. There is also no standard reporting of workforce data. Local information can be obtained by head counts or Whole Time Equivalents (WTE).
4.024 There are 4 and 8.55 WTE clinical oncologists in Swansea and Velindre NHS Trusts respectively. There are 2 paediatric oncologists based at Llandough Hospital and Community NHS Trust and one medical oncologist in Wales based at Ysbyty Gwynedd. Two medical oncology posts remain vacant in Wales having failed to attract any interest, reflecting the UK shortage in medical and clinical oncologists.

4.025 A number of Trusts stated that they required additional specialist sessions or staff in nursing, oncology and palliative care. Multidisciplinary cancer teams will require access to diagnostic and other support services which will have implications for the Professions Allied to Medicine, pharmacists and community-based social services. Even with reorganisation of the existing service, the clear view of service providers is that implementation of specialist multidisciplinary team working will require extra funding.

Clinical Audit

4.026 There is little evidence of on-going inter-Trust audit of clinical outcome of cancer patients although, at an all-Wales level, the recent Wales/Trent audit of colorectal cancer is widely praised. Haematologists also conduct all-Wales audit that is facilitated by a common database.

4.027 Centrally held patient episode data are inaccurate and clinical outcome data for cancer patients, when available, is collected and held by individual consultants.

Clinical Research

See The Baseline - Clinical Trials, Volume 2

4.028 All acute hospitals enter cancer patients into clinical trials but this varies considerably across Wales. The focus, from information provided by Trusts, is in South East Wales with 9 co-ordinators of MRC UK trials and over 100 clinical trials supported in hospitals based in and around Cardiff. Generally, clinicians expressed concerns regarding the time and administration involved when participating in clinical trials.

Information

See also The Baseline - Patient Numbers and Cancer Registration, Volume 2

4.029 With very few exceptions, hospitals are unable to provide comprehensive information relating to ‘who does what to whom and where?’.

4.030 There is a clear discrepancy between the centrally held information from the Patient Administration Systems (PAS), the Patient Episode Database for Wales (PEDW) and that held locally by Trusts and individual clinicians.

Contracting

See also The Baseline - Finance, Volume 2

4.031 The preliminary findings from Commissioners were such that, with the exception of the specialist cancer units, it soon became apparent that little reliable information could be obtained in relation to present investment in cancer services.

4.032 The existing contractual framework, by concentrating on overall quantum of cost, does not encourage Commissioner/Provider dialogue in relation to the real cost of patient specific protocols.

4.033 The current contracting basis raises the prospect for the patient of a lack of continuity of care as, dependent upon the treatment protocol, the patient may be subject to other contractual arrangements e.g. chemo- or radiotherapy under one contract with surgical interventions being the subject of another service contract.
CSEG recommendations for a high quality cancer service

An Integrated Cancer Service for Wales

**Introduction**

4.034 This report takes a broad brush approach in defining the characteristics of a high quality service for patients with cancer. In some instances such a service will already be working, in others there is much room for improvement. It is the aim of CSEG to use this report as a guide for the future. In order to begin to improve services along these guidelines, CSEG will have to work with Health Authorities as only they have the detailed local knowledge and, very importantly, they know their plans for development of other services.

4.035 The recommendations in this report are focused on changing the way in which patients with cancer are treated by the introduction of agreed guidelines and protocols, rather than where the treatment is provided, which inevitably concentrates on buildings and equipment.

4.036 This is not to underestimate the importance of buildings and equipment but rather to recognise that such changes will take time. The way forward in developing an All-Wales Cancer Service which will involve not only guidelines and protocols but will lead to buildings and equipment is outlined below. The change in methods of treatment and the acceptance of guidelines can be implemented more rapidly and this course is consequently the main thrust of this report.

**Configuration of Cancer Services**

4.037 This report depends on the principles outlined in “A Policy Framework for Commissioning Cancer Services” (the Calman-Hine report). The cancer unit as described in that report would equate with the acute general hospital mentioned here which has a multidisciplinary team, which is able to integrate primary and secondary care and provide appropriate rapid referral services.

4.038 Expertise is available in many locations and the development of multidisciplinary cancer teams must maximise patient access to comprehensive high quality care. Common treatment guidelines and protocols, based on the best available evidence, should be the basis of such care.

4.039 This report recommends an All Wales integrated service at Cancer Centre level. Services of the type described as Cancer Centre can be provided at three locations in Wales. These locations are Ysbyty Glan Clwyd (in co-operation, at least initially with the Christie Hospital NHS Trust and Clatterbridge Centre for Oncology in England), Swansea and Velindre NHS Trusts in Swansea and Cardiff respectively. The last two in association with their nearby large acute general hospitals, that is Morriston NHS Trust in Swansea and, in Cardiff, the University Hospital of Wales Healthcare NHS Trust, the University Dental Hospital NHS Trust and Llandough Hospital and Community NHS Trust. The All-Wales component will be achieved by agreed guidelines, protocols and audit with standard information of a high quality fed into the Wales Cancer Registry. Breast Test Wales offers an excellent model for this service.

4.040 In North Wales, the range of services available at Ysbyty Glan Clwyd will increase. All acute and community hospitals in North Wales will be expected to participate in the development of an integrated service covering a population of 0.65 million.
In Mid-Wales, the referral pattern for cancer treatment will be dependent upon access to multidisciplinary cancer site specific teams in neighbouring hospitals, whether in Wales or England. Once these teams have been identified, CSEG will need to work with the Health Authorities involved to implement the recommendations.

In South Wales, there should be the capability of treating all common cancers to the highest standard. Services will be centred on Swansea (Singleton and Morriston NHS Trusts) and Cardiff (Velindre, University Hospital of Wales, Llandough and the Dental School). Services for the rarer tumours, low volume necessitating one site for treatment, should be based where the expertise is available either in Swansea or in Cardiff. In this way Swansea and Cardiff will provide a single, integrated service for South Wales. The population available between Cardiff (1.5 million) and Swansea (0.75 million) will provide a research base enabling appropriate trials to be mounted.

Trusts working together need to agree, with their Health Authorities, where referral for specialised treatment of rare tumours should take place. Children with cancer should continue to have treatment directed by United Kingdom Children’s Cancer Study Group (UKCCSG) Centres.

Patients with cancer receiving care in Community Hospitals should have access to the full range of specialist services as required, provided to the standards outlined in this Report. Patients in Mid Wales who have their treatment in England must expect the same high standards to apply.

It will be important in delivering an integrated cancer service for patients in Wales that the Health Authorities ensure co-operation in the development of joint audit, agreed common protocols and take part in joint education and training.

Tumour site-specific professional groups should be established on an ‘All Wales’ basis. This is already in place for haematological malignancies with an All Wales network and data base. These groups, along with the Wales Cancer Registry and the CSEG Project Office, will have a key role in monitoring outcome, providing feedback to Directors of Public Health and clinicians to inform improvement in current clinical practice and facilitate the continuous improvement of treatment protocols.

Information systems collecting common data should be used across all Trusts and feed the Wales Cancer Registry. This will drive the adoption, development and audit of common treatment protocols at an All Wales level. The CSEG Project Office will have a role in facilitating this activity.

Common data collection should, in due course, embrace primary and community as well as secondary care.

CSEG will evolve into a new role. It will be for Health Authorities to clarify how this new role will be most helpful to them.
Management of The Major Cancers

Introduction

4.050 The following describes the generic recommendations, proposed by the Task Groups, aimed at achieving a high quality service for all the common cancers. These are derived from the specific Task Group recommendations (paragraphs 4.111-4.145). Findings arising from the service review are included alongside relevant recommendations. Further detail, including references are to be found in the Task Group Reports in Volume 2.

4.051 Throughout this report we will be emphasising the central role of communication and the availability of appropriate information. Recommendations are included for the management of childrens’ cancers but other rare cancers have been omitted in this initial report.

4.052 It is possible to identify important principles for the treatment of common cancers. These principles are the key feature of this report and in order to highlight them the following recommendations are those that apply throughout the service to all professionals involved in the treatment of cancer patients.

4.053 Cancer services start from the time of diagnosis.

Recommendations

Organisation

4.054 Organisational standards for care of patients with cancer must be defined for:

- all hospitals contributing to an integrated cancer service in Wales
- multidisciplinary cancer teams
- primary health care

There should be collaborative management between primary care practitioners and the specialists involved in diagnosis, assessment and treatment; with evidence of clear two-way communication pathways between primary and secondary care.

4.055 The multidisciplinary cancer team, subsequently referred to as the specialist team, must have operational links with the tertiary, radiotherapy referral centre to ensure efficient and prompt delivery of treatment programmes. This arrangement should be facilitated by the specialist oncologist who should have dedicated sessions with the multidisciplinary treatment team. To achieve this, regular joint or parallel clinical sessions should be arranged. Operational definitions for the specialist team and team working are provided in Appendix 4. Team membership is detailed in the Tumour site specific recommendations following (paragraphs 4.130-4.144) and the individual Task Group Reports (Volume 2).

4.056 Every hospital treating patients with cancer should identify a lead clinician.

4.057 Specialist teams must also designate a lead clinician who will identify the core and associate members of the team.

4.058 Specialist teams must be responsible for ensuring high-quality care for patients with cancer treated in hospital and will treat the majority of them.

4.059 To function as a specialist an individual professional, even after specialised training, must work as part of a specialist team and undertake continuing professional education and audit of practice in their specialist area. Evidence to support this activity must be available.

CSEG Findings

Fifteen hospitals and community Trusts, providing cancer services, have designated a lead clinician for cancer. Proforma responses indicate that lead clinicians have various responsibilities including for example, overseeing clinical protocol development, clinical audit, staff training, research, service development and liaising with colleagues, General Practitioners and Health Authorities.
4.060 All nurses should receive core training in the essentials of nursing patients with cancer. Specialist nurses in cancer care should hold appropriate post-registration qualifications in their special area of practice.

4.061 Consideration should be given to appointing specialist nurses to liaison posts with specialist teams to link with community services.

4.062 There are certain high cost clinical interventions, whose value is proven in quality of life and/or survival terms. For example, vascular arterial embolisation for bleeding from a tumour and neurosurgery for cordotomy to relieve pain. The benefits and risks of a procedure must be carefully considered for each patient.

4.063 Counselling, psychological support and palliative care services should be available as appropriate from the time of diagnosis.

**Guidelines**

Agreed guidelines and protocols are the driving force of this report.

4.064 Specialist teams should draw up written guidelines and protocols for the management of cancer. These should follow Welsh CSEG Task Group or UK guidelines where available and should be in consultation with clinicians at the local cancer centre and with the agreement of General Practitioners.

4.065 Specialist teams should develop systems for regular multidisciplinary audit to review agreed guidelines and protocols and monitor compliance and outcome.

4.066 Consideration should be given to setting up a system of external review of written guidelines and the work of the teams as a whole.

**Patient Referral**

4.067 All General Practitioners should have up-to-date, comprehensive information detailing specialist teams and associate members for their area.

4.068 The specialist team will need to work with other specialists and local General Practitioners to ensure that patients with suspicious symptoms can be seen for appropriate investigation promptly.

4.069 Referral policies and protocols that meet Welsh or UK standards should be agreed, used and audited locally. Feedback from audit must be made available to all professionals involved in cancer care, particularly General Practitioners.

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**CSEG Findings**

Local treatment guidelines and protocols are being developed and are generally welcomed as the basis for the future management of cancer patients. Responses from the proforma show that whilst 12 hospitals stated that they use locally or nationally agreed clinical protocols only 5 provided a comprehensive list. There is no mechanism for ensuring that common protocols, based on best available evidence of outcome, are adopted.

Patients and General Practitioners lack up-to-date information on where consultant led specialist cancer services are available and who provides the service.
Diagnosis

**4.070** Patients with cancer need prompt assessment and staging. The key indicator should be the time from receipt of referral to start of treatment (if carried out locally) or onward referral (if treatment carried out elsewhere).

**4.071** Specialist teams must have access to histopathology services. There should be facilities for external histopathology review of difficult cases. Consideration should be given to formalising routes of secondary referral of histological material within and without Wales.

**4.072** There is a need for more rapid access diagnostic services for all patients with suspicious symptoms. The use of ‘remote consultation’ should be considered for further development for example, telephone consultation between General Practitioner and specialist. Means of recording such communications and charging for this type of consultation should be evaluated.

**4.073** Methods of diagnosis, and staging should be in accordance with guidelines and protocols agreed with the local cancer centre and based on advice from Welsh CSEG Task Groups or UK guidelines where available.

Treatment

**4.074** Specialist teams should develop systems whereby individual patients can be assessed in a multidisciplinary fashion prior to treatment. This means that the treatment plan is discussed and agreed by the team, whilst the patient only needs to consult with the appropriate team member(s). The possibility of using modern technology for video conferences and image transfer to allow multidisciplinary assessment at a distance should be evaluated.

**4.075** Chemotherapy must only be given by clinicians experienced in the regimens used and where adequate, appropriately trained support staff (nursing, pharmacy) are available, in accordance with the Joint Council for Clinical Oncology (JCCO) criteria. In hospitals, where oncology time is available, the medical oncologist should be responsible for chemotherapy treatment.

**4.076** Radiotherapy must only be given by accredited clinical oncologists meeting the standards stipulated by the Royal College of Radiologists.

Follow-up

**4.077** The specialist team will review patients’ progress regularly. The team will, where appropriate, make explicit arrangements for long-term surveillance that will include input from both the patient and primary care.

**4.078** The care plan for follow-up after completion of primary treatment should be supported by information to patients, and include specific arrangements when patients are to be discharged.

CSEG Findings

From the GP survey, arrangements for rapid access diagnostic services are commended. Access to urology, ENT and dermatology are most difficult but, when access is achieved, General Practitioners express less concern about overall quality of these services. Diagnostic and treatment services for haematological malignancies, although relatively rare in general practice, are also considered to be good.

CSEG Findings

Cancer patients are treated in all acute general hospitals in Wales with referral to supra-regional centres in England for treatment of rare cancers for example, choriocarcinoma and bone tumours. Most Trusts report to have surgical specialists and there is evidence of redistribution of surgical work to support such specialisation. Clinicians expressed concern regarding the dilemma of providing both a good general surgical service whilst recognising the need for (anatomical) site specialisation when treating certain cancers.
Palliative Care

4.079 The patient, as the focus of care, should be involved in drawing up and the implementation of their care plan.

4.080 All professionals who hold NHS contracts at any level, including honorary, and are involved in the care of the patient must have clear clinical accountability within the framework of either the primary health care team (PHCT) when working at generalist level in the community, or the specialist palliative care team for those working as specialist professionals in hospital or community.

4.081 Where clinical services are provided by non-statutory organisations, service specifications must emphasise the need for such services to be supportive to the PHCT who must retain clinical responsibility for the patient in the community. Where clinical or counselling services are provided for patients in the community, they should be provided only with the prior knowledge of the General Practitioner. Clinical advice must be channelled via the General Practitioner.

4.082 All those providing care in association with any NHS services must work within a professional framework of clear accountability. Individuals, for example those working for a non-statutory agency, must have accredited training, properly constituted appointment procedures, access to continuing education and supervision. These procedures must be monitored by purchasers of the service.

4.083 A designated professional in each team should have specific liaison responsibilities at any one time about the care of an individual patient; the personnel involved will change at different phases of a patient’s illness.

4.084 PHCTs have continuing patient responsibility. Wherever the demands of palliative care exceed the resources available from the PHCT, then it is the duty of the General Practitioner to refer the patient to an appropriate specialist service for the provision of care that may be community-based. Such referral could include specific provision of care out-of-hours.

4.085 Formal partnerships should be forged between different small providers to form a functional unit for the provision of specialist palliative care services.

4.086 Patients at home can require rapid and frequent changes in medication to maintain optimal symptom control. The supply of drugs to achieve this and avoid wastage may require a revision of pharmacy services and regulations.

CSEG Findings
Forty-two percent of those answering the GP survey consider that access to palliative care inpatient services is inadequate or grossly inadequate. Quality of service, when access is achieved, is generally fairly well rated. The important contribution of the non-statutory voluntary sector in the care of cancer patients is recognised. They provide well over 50% of all palliative care services. The recent review of Palliative Care Services in Wales whilst identifying all agencies involved highlights a lack of accurate, centrally held information regarding personnel and services provided. Specialist hospice services have developed on an ad hoc basis and are difficult to evaluate because of the complexity of care needed. The effectiveness of hospital follow-up and community care are also not adequately evaluated and patterns of service provision vary.
Communication

4.087 Communication between consultant and patient of diagnosis and prognosis should be carried out in strict confidence away from open wards and corridors. Patients should be supported by a friend, relative or appropriately trained nurse.

4.088 The patient’s view should always be obtained when deciding a plan for treatment. The quality of life they may expect should be a major factor in determining this plan. Consequently patients, their families and carers need to be better informed about treatment, available options, potential outcomes and support services.

4.089 Written and other forms of information should be given to patients about their type of cancer, their treatment plan and other aspects of care. Patients at home should be given a contact name and telephone number in cases of emergency.

4.090 Information in an appropriate form should be given to patients on discharge from hospital, providing information on support groups, aftercare, benefits and entitlements, etc. Information packs should be used in addition to good spoken communication.

4.091 There should be a single, multiprofessional form of patient held record. This should be in a rapidly readable format, up-to-date and accessible to all members of the team(s) caring for the patient.

4.092 The patient record should contain current problems and focus around care planning and evaluation, with the information told to the patient and family clearly documented.

4.093 There should be two-way communications between specialist and generalist teams wherever the patient is located.

4.094 There is a need for further research to evaluate and improve communication with patients with cancer.

4.095 A very large number of individuals and organisations are involved in the care of patients with cancer, and the communication between them is largely unstructured and ad hoc. Further work is needed to look at the method, speed, content, validity and accuracy of such communication and identify ways to improve.

4.096 All personnel involved in patient care should have training and updating in communication skills.

Research

4.097 All specialist teams should be actively involved in clinical research. Entry of patients into clinical trials should be facilitated. Management will need to recognise that adequate administrative support is required.

CSEG Findings

The Information Task Group found that communication between patients and professionals and between professionals is widely perceived as requiring improvement. The increasing numbers of telephone calls to the Tenovus Helpline requesting information is further evidence for this. The patient focus groups reported that there are many instances, in different parts of Wales, of patients being told their diagnosis and prognosis in open wards and corridors. Contact with others who have cancer can be of great value. In 1995 the Health Information Wales database held information on 60 cancer support groups throughout Wales.

CSEG Findings

All acute hospitals enter cancer patients into clinical trials but this varies considerably across Wales. The focus, from information provided by Trusts, is in South East Wales with 9 co-ordinators of MRC UK trials and over 100 clinical trials supported in hospitals based in and around Cardiff. Generally, clinicians expressed concerns regarding the time and administration involved when participating in clinical trials.
Research is essential to provide the evidence base for future service developments. This will normally be carried out in conjunction with Welsh or UK research programmes. Collaboration between multidisciplinary cancer teams on an ‘All Wales’ basis, to plan clinical trials and associated research must be facilitated.

Information Issues

All new cases, with a confirmed diagnosis, should be registered, via the specialist teams, with the hospital clinical information system. This should be linked to the Wales Cancer Registry.

Specialist teams should collect data on all patients diagnosed with cancer in their hospital and should monitor their outcome. Such information should be available, in a common format, to the Wales Cancer Registry.

Mechanisms should be in place to ensure that relevant information and results are sent to the clinic in advance of appointments to avoid delays, disappointment and further appointments.

Computerised systems and drug formularies must be compatible through all parts of the clinical service.

Training

Continuing medical and nursing education for the PHCT should be developed with the support of local tutors and local specialist resources. One or more All-Wales facilitators for educational activities for PHCTs should be considered. Specialists in palliative care should expect to be involved on a regular basis in educational activities, such as case-based discussion. Clinical audit must be integrated with educational programmes, and should be utilised both as a method of educational needs assessment, and to assess the impact of educational programmes for the PHCT and its members.

Developments in genetics over the next decade will have a major impact on the work of PHCTs. In particular, PHCTs will be involved in giving advice about risks of cancer to individual patients or families, and the need for appropriate investigation and follow-up. PHCTs will require specific educational programmes to cover these developments in genetics; PHCTs must be involved in the debate both about the principles of any new service provision and ethical issues involved.

All nurses should receive core training in the essentials of nursing patients with cancer, including communication skills.

Designated educational pathways should be developed for nurses specialising in cancer and palliative care to enable them to practise as advanced or specialist practitioners. Specialist nurses in cancer care should hold appropriate post registration qualifications in their special area of practice.

Continuing training should be provided for all professionals involved in the provision of multiprofessional, multidisciplinary cancer care.

CSEG Findings

There is no evidence of on-going inter-Trust audit of clinical outcome of cancer patients. At an all-Wales level, the Wales/Trent audit of colorectal cancer is widely praised. Haematologists also conduct all-Wales audit which is facilitated by a common database. Clinicians frequently voiced concern over the lack of up-to-date cancer registration and inaccuracies in the Patient Episode Database. Many Trusts found difficulty in providing information on the numbers of their new cancer patients as opposed to patient episodes of care. With very few exceptions, hospitals are unable to provide comprehensive information relating to ‘who does what to whom and where?’. Clinical outcome data for cancer patients are a matter for individual consultants.

Continuing training of professionals is essential throughout the service. The GP survey reports that access to CME for Cancer Care in Wales for GPs was felt to be inadequate or very inadequate by 33% of respondents, although it was noticeable that CME was thought to be better where there were strong local services in palliative care - suggesting that local consultant and other staff are having a specific input to the programmes. A number of specialist nursing posts were identified with the vast majority having attained an appropriate post-registration qualification. There is a wide spread of courses undertaken but there is no evidence that investment in training was based on needs assessment. The number of courses taken does not necessarily equate with the population density or areas of excellence.
**Contracting**

4.108 Registration of cancers with the Wales Cancer Registry is essential and should be incorporated into the contracting process.

4.109 Reorganisation of services to facilitate a multidisciplinary team approach will require a time commitment from team members to attend regular team meetings. This should be reflected in job plans and contracting.

4.110 A pilot study should be carried out with contracts for cancer services set under a single primary contract. The contract should be with a hospital or association of hospitals which have the responsibility to ensure delivery of the complete episode of care. This should include the ability to sub-contract services as appropriate. Contracting and costing should be related to cancer site and based upon evidence-based clinical guidelines and protocols.

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**CSEG Findings**

The existing contractual framework, by concentrating on overall quantum of cost, does not encourage Commissioner/Provider dialogue in relation to the real cost per patient of cancer site specific treatment protocols. Diagnostic Related Groups (DRG) are insufficiently sensitive to variations in case mix to provide this flexibility and more sensitive groupings which relate more precisely to areas and types of treatment are required. The current contracting basis raises the prospect for the patient of a lack of continuity of care as, dependent upon the treatment protocol, the patient may be subject to other contractual arrangements e.g. chemo- or radiotherapy under one contract with surgical interventions being the subject of another service contract.

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**KEY MESSAGES**

- Screening and educational programmes should promote the clear message that cancer, where possible, can be prevented.
- Communication with patients and between professionals in all sectors of the service must be improved.
- Cancer treatment should be delivered by multidisciplinary cancer teams following agreed guidelines and protocols. Ideally, teams should be based at one-site, failing this, team members should hold joint clinics. The essential component should be that patients, regardless of location of the team, receive treatment that follows agreed guidelines and protocols.
Specific Task Group Recommendations
See also individual Task Group Reports, Volume 2

Prevention and Screening

4.111 The level of cancer incidence is understandably a matter of public concern, and approximately a third of the population will develop cancer at some stage of their lives. There is a need therefore to concentrate on reduction of risk factors, screening for precancerous/early disease and early detection.

4.112 Primary prevention involves stopping the disease process before it starts. Screening or secondary prevention involves detecting the disease early in its course when it is easier to cure.

Recommendations for Prevention

• Within the field of Health Promotion, cancer prevention should be recognised as a priority. The EU 10 point Cancer Code should be supported.

• It will be important, in co-ordinating the major aspects of cancer prevention on an All Wales basis, to bring together relevant public health activities of Health Authorities and other agencies. Mechanisms will need to be developed to ensure effective integration of national with local activities.

Recommendations for Screening

• Current targets for uptake of breast and cervical screening should be supported.

• Screening programmes should only be undertaken on the basis of research and where effective treatments are available.

• The revenue consequences of screening aimed at early detection of cancer and subsequent treatment costs must be agreed with commissioners prior to embarking on a screening programme.

• Targeted screening for cancer families and genetic testing should be considered as part of the general services for the particular speciality, not as a population screen.

• Individuals need to be very clear as to what the screening programmes offer and that screening is not prevention.

Evidence base
The Patient View

4.113 The real problem for many people, identified by patient focus groups, was obtaining information about where was ‘the best place’ for treatment and why. Members of all groups agreed they would travel any distance for diagnostic and surgical treatment if they knew they were going to ‘the best place’, acknowledged for expertise and excellence. In general terms, a journey of 30 minutes was deemed acceptable to the General Practitioner/hospital for routine follow up, but journeys of over an hour were to be avoided for those undergoing debilitating treatment. ‘It is a myth that everyone has the use of a car’.

4.114 The majority of groups also expressed genuine concern at the lack of information and the need to review methods of communication with patients. Evidence provided by the Tenovus Freephone Helpline Service showed that in 1995 approximately 10,000 calls were received. The main reasons given for calling focused on:

- Cancer information - prevention, diagnosis, treatment, prognosis
- Social support (financial advice)
- Resources available (how to care)
- Counselling
- Health professionals seeking information

Recommendations

- Mechanisms should be in place to ensure that results and case notes are sent to the relevant hospital in advance of appointments to avoid delays, disappointment and further appointments.
- Transport should be arranged for any length of distance for diagnostic and surgical treatment, taking into account the individual patient’s needs. A journey of 30 minutes would be acceptable to the General Practitioner or hospital. Journeys of over an hour should be avoided for patients undergoing debilitating treatment.
- Specialists and the location of specialist cancer site specific multidisciplinary teams should be identified.
- The communication of a patient’s diagnosis and prognosis should be carried out in strict confidence away from open wards and corridors. Medical and nursing staff should receive training in communication.
- Communication should be improved between specialists and General Practitioners following a patient’s discharge from hospital.
- Methods of communication with patients should be reviewed. Information packs should be given to patients on discharge from hospital, providing information on for example, support groups, aftercare, benefits and entitlements.

Evidence base

1. The National Cancer Alliance
2. Task Group Patient Focus Groups
3. Published papers
General Practice/Primary Health Care Team

A quarter of all deaths in the UK are caused by cancer, and one in three people will develop cancer at some stage in their lives. All these patients will be registered with General Practitioners, who have to provide the necessary initial assessment, and co-ordination of services for the patient, in line with the general principles described earlier. In some cases, the involvement of the General Practitioner in the care of an individual patient who has developed cancer may be relatively short-term, although intensive and demanding. In other cases, the patient will survive for many years, yet the fact that the patient has suffered a potentially life threatening illness may cause a range of other problems in the patient’s care, or the care of his or her family. Further, the primary health care team (PHCT) must consider and develop a range of services relating to the prevention and co-ordination of primary care to the population - this work is quite extensive and involves all members of the PHCT in developing and implementing appropriate policies. Much of this is related to prevention, to co-ordination of diagnostic services, and to co-ordination of care of the patient and family.

Recommendations

- There is a continuing need for PHCTs to provide an integrated service of cancer prevention, early diagnosis, and co-ordination of management for patients with cancer.
- General Practitioners should set priorities for advice on cancer prevention. High risk patients should be identified and advised appropriately.
- PHC teamwork should be developed. This is not something that is unique to cancer care. Other specialist workers in contact with the PHCT must be sensitive to, and respect the generalist nature of the role of PHCT members.
- A clinical lead worker should be identified for each patient receiving palliative care in the community. This individual should usually be drawn from the generic PHCT; specialist advice should be delivered via the generic PHCT.
- The PHCT is fundamental both to the organisation and delivery of clinical services for patients with cancer being cared for in the community. Where clinical services are provided by non-statutory organisations, these must be supportive to the PHCT who must retain clinical responsibility for the patient in the community, (except on the rare occasion where a specific referral and hand-over is made to a Specialist community service). Where clinical or counselling services are provided for patients in the community by specialist or non-statutory services, they should be provided only with the prior knowledge of the PHCT. Clinical advice must be channelled via the PHCT lead worker.
- There is a real need for improving communication between Primary and Secondary Care. Information should be timely and relevant. Minimum content of information between General Practitioner and hospital is:
  a) diagnosis
  b) current problem
  c) proposed management plan - including follow-up
  d) what the patient has been told
  e) other agencies involved
  f) current medication and treatment
A local directory of services should be available to the PHCT.
- Experiments in improving communication between Primary and Secondary Care based on modern Information Technology should proceed, with due regard to the requirements for data protection and security.
• There is a need for more provision of ‘fast-track’ diagnostic services, especially in urology and ENT. This does not necessarily mean a separate service, but does mean a quick response to a request from a General Practitioner for an urgent opinion. Not all urgent opinions can be categorised into specific symptoms, such as haematuria, rectal bleeding, etc. The use of ‘remote consultation’ should be considered for further development for example, telephone consultation between General Practitioner and Specialist. This type of consultation is much commoner in other countries than in the UK, and we suggest that secondary care services should consider providing facilities for such consultations.

• CME/CNE for the PHCT should be developed with the support of local tutors and local specialist resources. One or more All-Wales facilitators for educational activities for PHCTs should be considered, and specialists in palliative care should expect to be involved on a regular basis in educational activities, such as case-based discussion. Clinical audit must be integrated with educational programmes, and should be utilised both as a method of educational needs assessment, and to assess the impact of educational programmes for the PHCT and its members.

• Developments in genetics over the next decade will have a major impact on the work of PHCTs, especially in relation to provision of advice about risks of cancer (and other diseases) for individual patients or families and the need for appropriate investigation and follow-up of symptomless patients at risk. PHCTs will require specific educational programmes in respect of the developments in genetics over the next decade; PHCTs must be involved in the debate both about the principles of any new service provision, and the ethical issues involved.

• The needs of General Practitioner Fund-Holders for advice on purchasing care for patients with cancer should be addressed - especially if total fund-holding is introduced.

Evidence base
1. GP Task Group Survey
2. Reports of Professional bodies
3. CSEG view
4. Published reports on cancer care
5. Published health care planning documents
Diagnostics

4.116 Clinical Radiology provides diagnostic imaging information about anatomy, function, disease and an increasing amount of interventional diagnostic and minimally invasive therapy work. A significant proportion of the daily workload of any department of radiology deals with the diagnosis, staging, tumour localisation prior to therapy and follow-up of malignant disease.

4.117 Pathology has a major role in the diagnosis of cancer and also in monitoring subsequent treatment and in supporting the general care of cancer patients who may be suffering not only from their tumour and its complications but also other pathologies.

4.118 Patients with cancer present to the health service both by referral from General Practitioners and as emergencies to virtually all clinical disciplines and with a wide variety of often non specific symptoms. Clinicians rely heavily on diagnostic services including Pathology and Radiology in arriving at a diagnosis. It follows from this that it is impossible to divorce pathology services related to the initial diagnosis of cancer from those required for diagnosis of other conditions.

4.119 The necessity for a comprehensive diagnostic service to support all clinical activity is emphasised by the Royal College of Pathologists and is recognised by others who have assessed current pathology provision. The Diagnostic Report in Volume 2 reviews the roles of imaging and pathology.

4.120 The future emphasis should be on reshaping processes within the existing services, in particular multidisciplinary working guided by protocols with clear channels for secondary and tertiary referral.

Recommendations

Pathology

- Multidisciplinary cancer site specific teams will require the services of all four main pathology disciplines (haematology, medical biochemistry, microbiology and histopathology/cytopathology). In addition the local cancer centre will require more specialised services such as medical genetics, cytogenetics and immunology.

- Purchasers should look for evidence of quality standards in the service via participation in accreditation schemes such as Clinical Pathology Accreditation (UK) Ltd or the Kings Fund Organisational Accreditation Scheme. Other schemes include National Quality Control Schemes, External Quality Assessment and Continuing Education Programmes. Most of these already exist for the major pathology disciplines.

- The promotion of multidisciplinary team working and protocol development is seen as the way forward for cancer services and should include pathologists of all disciplines. This may have to be on the basis of co-operation between centres and units or between adjacent units.

- Greater emphasis needs to be placed on rapid access to pathology services by General Practitioners. This may mean direct access to the laboratory and its facilities or through the medium of one stop multidisciplinary clinics.

Medical Biochemistry/Chemical Pathology

- There may be some scope for centralisation of tumour marker work within Wales.

Haematology

- Special support will be required for centres involved in bone marrow transplants.

- The setting up of a formal scheme for second opinions on histopathological diagnosis of all lymphoid malignancy should be considered.
Microbiology

- Infection control teams are an essential part of services and should be specified in contracts.
- A full range of bacteriology, virology and mycology needs to be available in all units or centres dealing with immuno-compromised patients during cancer therapy.

Histology/cytology

- Histopathology is central to the diagnosis of most malignancies. Histopathologists need to be involved in all multidisciplinary teams drawing up protocols for diagnosis and management.
- Protocols for specialist referral of histopathological material may be necessary to safeguard this essential activity.
- Sub-specialisation of histopathologists is to be encouraged throughout the service and will be essential in cancer centres.
- There may be scope for centralisation of some immuno-histochemistry within Wales. The introduction of newer techniques such as molecular biology will also need to be addressed on an all Wales basis.
- The protocols for handling and reporting of pathological material developed by Breast Test Wales are commended and should be used as models for other tumour sites.
- There may be scope for further centralisation of cervical screening laboratory services as outlined in the Report of the Expert Advisory Group on Cervical Screening.

Imaging

- Multidisciplinary cancer site specific specialist teams should include, where appropriate, radiologists and radiographers.
- A lead radiologist should be identified within each specialist cancer team as the focal point for communication regarding imaging information between each cancer team and the local cancer centre.
- Each specialist cancer team should advise on and establish responsibility for:
  a) Referral patterns for imaging (e.g. via specialist clinic or direct from primary care)
  b) Appropriate waiting times for imaging investigations
  c) Diagnostic protocols and guidelines
  d) Auditing and monitoring of standards and outcomes
  e) Monitoring of continuing education and training
  f) Stimulating and co-ordinating research activity
- Lead radiologists should establish links between cancer teams with the key objective of providing quality, consistency and convenience of imaging services to patients throughout Wales.

Evidence base

1. Consensus within Wales derived from results of surveys carried out in both Pathology & Radiology.
2. Guidance for Purchasers of Pathology Services. The Royal College of Pathologists 1995
3. Pathology Services in Wales - Guidance for the Purchasing of Pathology Services for the NHS in Wales - Value for Money Unit, NHS Wales 1995
5. Pathology Reporting in Breast Cancer Screening NHSBSP 1995
7. Implementing ‘A Policy Framework for Cancer Services’ North West Regional Health Authority 1995
Nursing

Cancer nurses are able to effect health gain, both as co-ordinators of multi-disciplinary teams and as practitioners in their own right. Examples of health gain from the provision of nursing care include:

a) alleviation of psychological distress associated with breast cancer by early detection and help with identified problems
b) improved symptom control for the terminally ill with early involvement of specialists in palliative care nursing
c) improved functional ability for patients with cancer of the colon through the psycho-educational interventions of stoma nurses
d) improved continuity of care for patients undergoing chemotherapy through the development of the role of the chemotherapy nurse
e) improved quality of life for patients through the application of techniques for the reduction of lymphoedema developed by lymphoedema nurses

Recommendations

• Specialist nurses in cancer care should be available in all health care settings.
• Specialist nurses in cancer care should hold appropriate post registration qualifications in their special area of practice.
• All nurses should receive core training in the essentials of nursing patients with cancer.
• Clearly designated educational pathways should be developed for nurses specialising in cancer and palliative care to enable them to practise as advanced or specialist practitioners.
• The education curriculum should ensure specific skills acquisition as well as attainment at an academic level.
• Posts such as Lecturer-Practitioners should be developed in all health care settings to assist in narrowing the theory practice gap.
• All Wales and local network groups should be developed for nurses working in cancer care.
• Nationally recognised nursing protocols and standards should be adapted to ensure consistency and quality of care.
• Nursing standards and protocols should receive regular audit and comparison across Wales.
• Clinical practice should be evaluated to identify best practice, clinical effectiveness and outcome.
• Common minimum data sets should be developed to assist in workforce planning.
• Consideration should be given to appointing specialist nurses to liaison posts with specialist teams to link with community services.

Evidence base

1. RCN Standards of Care
2. Caring for the Future: Nursing Agenda NHS Wales 1995
4. UKCC Guidance. Specialist Practitioner 1994
5. Strategy for Nursing in Wales
6. Published Papers
Palliative Care

4.122 The provision of palliative care involves a generic service applicable to patients irrespective of the site of their cancer, but determined by the rate of disease progression and the impact that cancer has on the patient’s quality of life in many domains including physical, emotional, social and spiritual.

4.123 Palliative care services also have a responsibility beyond cancer to other patients with advancing life-threatening disease: care extends to the patient’s family and beyond the patient’s death into bereavement care. Therefore multi-professional specialist palliative care service delivery must be widely available to enable all those dealing with patients to access specialist advice and help and to ensure the patient’s quality of life is optimised even in advanced disease.

Recommendations

- The specialist multiprofessional palliative care team should work across geographical and administrative boundaries.
- There should be clearly defined roles for the different professionals within the team and the way they relate to other teams.
- There must be two-way communications with primary, secondary, hospice and nursing home care.
- All professionals who hold NHS contracts at any level, including honorary, and are involved in the care of the patient in the community, but are not members of the specialist palliative care team, must have clear clinical accountability within the framework of the primary health care team (PHCT). If specialists in palliative care, they must have clear accountability within the framework of a multiprofessional specialist palliative care team; in many areas this will require partnerships being forged between different small specialist palliative care teams.
- All those providing care in association with any NHS services must work within a professional framework of clear accountability. Individuals, for example those working for a non-statutory agency, must have accredited training, properly constituted appointment procedures, continuing education and supervision. These procedures must be monitored by purchasers.
- PHCTs have continuing patient responsibility. Wherever the demands of palliative care exceed the resources available from the PHCT, then it is the duty of the General Practitioner to refer the patient to an appropriate specialist service for the provision of care, this may be community-based. Such referral could include specific provision of care out-of-hours.
- Formal partnerships should be forged between different small providers to form a functional multiprofessional unit for the provision of specialist palliative care services.
- Patients at home can require rapid and frequent changes in medication to maintain optimal symptom control. The supply of drugs to achieve this and avoid wastage may require a revision of pharmacy services and regulations.
- Patient-held records should be used as a means of communication.
- Within the specialist team a single core form of documentation should be used. This multiprofessional patient record should be in a rapidly readable format, be up-to-date and be accessible to all members of the team caring for the patient.
- The record should contain current problems and focus around care planning and evaluation, with the information told to patient and family clearly documented. The patient, as the focus of care, should be involved in drawing up and the implementation of their care plan.
- Computerised systems and drug formularies must be compatible through all parts of the clinical service.
• A key-worker in the support team may be separate from the lead clinician.
• Where General Practitioners use deputising services the increased out of hours workload on community palliative care teams should be recognised in contracts.
• Defined links and co-operative working between oncology and palliative care services must exist. The evaluation of need should support service developments; this should be undertaken with the local providers at specialist and non-specialist level and must recognise the role of specialist palliative care in care of non-cancer patients.
• In each district a specific agency should take responsibility to co-ordinate service development and planning and evaluate standards of care.
• The multidisciplinary team should audit quality standards and ensure duplication of service provision is avoided. Through education, clinical effectiveness will result from the implementation of research into clinical practice.

**Evidence base**

1. Published papers
2. Welsh Health Planning Forum 1990
3. National Cancer Alliance 1996
Quality of Life

4.124 The term “Quality of Life” extends both to the impact of treatment and side effects and to the recognition of the patient as an individual, as a whole person, body, mind and spirit. It can only be described and measured in individual terms and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions; therefore a perception of Quality of Life must consider all areas of life and experience.

4.125 The quality of life of patients and their families must be considered in all areas of service provision. Individualised approaches to assessing quality of life can contribute greatly to a clinical management plan for an individual patient.

Recommendations

• Patients’ quality of life must be considered in all service provision.
• It is unethical for professionals to make qualitative judgements about a patient’s quality of life without seeking the views of the patient.
• Idiographic (individualised) approaches to assessing Quality of Life can contribute greatly to a clinical management plan for an individual patient.
• Normothetic scales to assess Quality of Life are useful for research and essential in clinical trials; the limitations of each tool must be considered.
• Good communication skills are a core requirement of every clinician. Training in communication skills should be mandatory in continuing postgraduate education of each professional.
• Children and adolescents, as relatives, have needs that must be addressed by adult service providers.
• All those in contact with the patient and their families must show sensitivity and respect. The damage caused by insensitive handling of a patient and family at diagnosis or during treatment has repercussions in the increased morbidity of the bereaved.
• All professionals must adopt a patient centred rather than a specialist centred approach. This requires integrated team working.
• Organisational standards must be clearly defined for the local cancer centre, multidisciplinary cancer teams and General Practitioner services.
• Integrated cancer services should include an active educational and research role in qualitative components of care.
• Audit by multidisciplinary cancer teams must address qualitative aspects of physical and psychosocial care at all stages of disease.
• The number of cancelled operating lists must be decreased.
• Adequate written information for patients should be readily available.
• Care should be planned and evaluated by the multiprofessional team.
• There are certain high cost clinical interventions, whose value is proven in quality of life and/or survival terms. For example:
  a) vascular arterial embolisation for bleeding from a tumour
  b) neurosurgery for (1) cordotomy to relieve pain, (2) removal of isolated cerebellar metastasis and (3) decompression of spinal cord with high compression from the tumour.

The benefits and risks of a procedure must be carefully thought about for each patient. The ethical issues in service provision require consideration.

Evidence base

1. Published papers
2. RCN Standards of Care Project 1991
3. National Cancer Alliance 1996
4. National Hospice Council publications
5. House of Lords Select Committee on Medical Ethics 1995
Information Issues

4.126 A very large number of individuals and organisations are involved in the care of patients with cancer, and the communication between them is largely unstructured and ad hoc. Ideally, there should be integrated care based on multidisciplinary guidelines with similarly patient focused integrated record keeping.

4.127 There is growing agreement at national and local level about the importance of communication with, and information given to patients, their families and carers. The findings from national studies of the information needs of people with cancer have been replicated at the local level. Whether in future cancer treatment and care are given in specialist cancer centres, cancer units in district general hospitals or in primary care as Calman/Hine proposes, there will still be information needs. While some studies have evaluated particular ways of giving information, further research is needed to evaluate cost-effectiveness and outcomes in terms of quality of life, patient expectations and resource usage.

Recommendations

- There is a need for further research to evaluate and improve communication with patients with cancer. The concept of the key worker in particular needs to be evaluated.

- A very large number of individuals and organisations are involved in the care of patients with cancer and the communication between them is largely unstructured and ad hoc. Further work is needed to look at the method, speed, content, validity and accuracy of such communication, and identify ways to improve it. Particular issues of concern include the following:
  a) Much communication takes place by telephone, and details of such conversations are often not recorded.
  b) Paper communication between primary and secondary care is slow and often incomplete. Minimum standards need to be identified, both for speed and content of communication.
  c) Improvement in communication between members of teams within hospital is more in need of improvement than the communication between teams in the community.

- There is a need for patient focused records which are shared between professionals and organisations. Although these are likely to be the key to improvement, they will be dependent upon more integrated working between professionals. Ways to take this forward need to be explored, particularly the concept of key workers and the wider implementation of clinical information systems.

- Until fully developed electronic solutions are in place, greater attention should be made to improving paper processes, particularly more use of the fax machine.

- There is a need to make available to all professionals, details of facilities and resources available for the management of patients with cancer. These details need to be updated on a regular basis.

- The paucity of valid aggregate activity, process and outcome data is widely acknowledged. While this issue has not been addressed by this Task Group, it is clear that the availability of such data will be dependent on the wide implementation of patient focused clinical information systems, which could form the basis for local interactive registers of cancer patients.

Evidence base

1. Published papers
2. Feedback from patients
3. Feedback from professionals
4. GP Task Group Survey
Finance

4.128 The development and enhancement of cancer service treatment is founded upon the identification and promotion of ‘Good Practice’. With the resource constraints and the competing demands for resources within the NHS it is essential to ensure that specialist service areas can accurately identify costs and investment in a manner which can promote meaningful discussion about resource utilisation between clinical experts. The current contract basis raises the prospect for the patient of a lack of continuity of care as, dependent upon the treatment protocol, the patient may be subject to other contractual arrangements e.g. chemo- or radiotherapy under one contract with surgical interventions being the subject of another service contract.

4.129 The basis for costing of cancer services needs to be more precisely related to cancer treatment areas. The methodology should provide financial information of relevance to both commissioners and providers of cancer services, be compatible with clinical management of patient services and use a currency compatible with service delivery. The contracting framework has not only to recognise the complexity of treatment in relation to cancer but also appear seamless to the patient.

Recommendations

• A pilot study should be carried out with contracts for cancer services set under a single primary contract. The contract should be with the hospital or association of hospitals which have the responsibility to ensure delivery of the complete episode of care. This should include the ability to sub-contract services as appropriate. Contracting and costing should be related to cancer site and based upon evidence-based clinical guidelines and protocols

Evidence base

1. Feedback from Directors of Finance and Contracting Departments within NHS Wales.
2. Published Paper
Management of Gastrointestinal Cancer

4.130 The majority of gastrointestinal (GI) cancers present to acute general hospitals. Many patients present electively, with non-specific symptoms. They may, therefore, be seen and undergo investigation as part of a much larger patient population, the vast majority of whom do not have cancer. In addition, a significant number of GI cancer patients present with acute symptoms and are admitted to hospital as emergencies. In both elective and emergency care therefore, the initial management may be given by clinicians other than GI specialists.

4.131 In Wales, with many relatively small DGHs, individual units can avoid isolation and provide an expert service by close association with a cancer centre, working to joint protocols and sharing joint oncology appointments.

4.132 The following summarises the key standards of service provision for patients with gastrointestinal cancer. Further detail, references and specific recommendations regarding the individual cancer sites, are contained in the GI Report attached in Volume 2.

Recommendations

- Methods of diagnosis, staging and treatment should be in accordance with guidelines agreed with the cancer centre and based, where available, on advice from National Specialist Groups, The Cochrane Centre and The Clinical Outcomes Group (Cancer Sub Group) etc.

- Patients with gastrointestinal cancer should have the benefits of multidisciplinary team care. Such care enhances the possibility of a broader based decision making process compared with a non team approach. All aspects of management are given due weight and the ‘maverick’ opinion is less likely to prevail in a group. The core team should include site specific specialists in surgery (one of whom will usually be the team leader), oncology, pathology, radiology and stoma/colorectal nursing. Associates, who should be involved with selective patients, include: consultants and nurse specialists in palliative care, endoscopy, gastroenterology, care of the elderly and clinical genetics, a clinical trials nurse or data manager, oncology pharmacist, oncology nurse and a clinical psychologist. Clerical and IT support are an integral part of the team.

- Designated specialist rapid access clinics (upper GI endoscopy, rectal) enable diagnosis at an early stage which is crucial for a favourable outcome.

- Accurate preoperative staging is necessary to avoid unnecessary or inappropriate major surgery, and to plan multimodal therapy. It determines eligibility for entry into clinical trials. Staging is also vital in comparing treatments between and within units. Staging protocols should be agreed on an All Wales basis and monitored by audit.
• Histopathological staging is fundamental in deciding the need for adjuvant or additional therapy, entry into clinical trials, comparison of outcome between units and determining prognosis for all forms of gastrointestinal malignancy. A lead pathologist, with sufficient time to devote to gastrointestinal cancer, is an integral member of the team. Histopathology reporting should be based on the recommendations of National Groups (eg. UK CCCR) when available. Consideration should be given to template reporting to ensure a uniform standard.

• Multimodal therapy characterises the modern management of malignant tumours of the gastrointestinal tract. Various combinations of multimodal adjuvant therapy are under review and such treatments should be used in association with the cancer centre by joint protocol, preferably within a clinical trial. For advanced tumours, evidence increasingly supports preoperative multimodality therapy with resection in responders.

• The multidisciplinary cancer team will need to meet regularly to review guidelines, audit outcome, provide training and education and assess communication links. Regional collaboration between teams on an ‘All Wales’ basis to plan clinical trials and associated research strategies should be encouraged.

Evidence base
2. Published evidence
3. Consensus in Wales with review of the GI task group report by specialist clinicians in Wales followed by consultation with all members of the Welsh Surgical Society
Management of Lung Cancer

4.133 Lung cancer is unique in having a single, overriding and identifiable cause, i.e. smoking, and is therefore almost entirely preventable. Although other risk factors have been postulated, e.g. radon gas and atmospheric pollution the effect of these is small in relation to smoking.

4.134 It is the government’s aim to reduce the incidence of lung cancer by reducing the number of adults who smoke to less than 20% by the year 2000. It is important to note however, that the effects of smoking continue long after the habit has stopped. Therefore, even if there were a decrease in the number of smokers, the incidence of lung cancer would remain high for many years. This would be largely due to a rise in incidence in females.

4.135 The majority of treatments for lung cancer are purely palliative. Inadequate care and inappropriate treatment may lead to poor symptom control, poor quality of life and greater distress for people with lung cancer and their families. Improved cancer services may therefore lead to improved quality of life for people with lung cancer. This is perhaps the area with the greatest potential for immediate benefits.

4.136 Although only a small minority of patients are curable it is critical that this group are accurately identified.

Recommendations

- Any hospital treating lung cancer should identify a lead clinician for lung cancer who will normally be a respiratory physician.
- The lead clinician for lung cancer will, with other clinicians involved in the treatment of lung cancer, form a designated lung cancer team.
- The lung cancer team will be responsible for ensuring high-quality care for patients with lung cancer treated in the hospital and will treat the majority of them.
- The team members will normally comprise: a respiratory physician (the lead clinician for lung cancer), a clinical oncologist and a thoracic surgeon. It may also include a medical oncologist, a respiratory specialist nurse, a palliative care physician and other staff.
- The lung cancer team will need regular input from the thoracic surgeon. The mechanism for this input may vary from hospital to hospital. Regular joint or parallel clinical sessions are ideal and should be encouraged.
- The lung cancer team will draw up written guidelines for the management of lung cancer. This will be done in consultation with clinicians at the local cancer centre and with GPs.
- The lung cancer team will need to work with the local GPs to ensure patients are referred appropriately and promptly. Separate guidelines on referral may be helpful.
- The lung cancer team will develop a system whereby individual patients can be assessed in a multi-disciplinary fashion prior to treatment. The nature of this system may vary from hospital to hospital. The possibility of using modern technology for video conferences and image transfer to allow multi-disciplinary assessment at a distance should be evaluated.
• The lung cancer team will develop a system for regular multidisciplinary audit to review the agreed guidelines and monitor outcome.
• Patients with lung cancer need prompt assessment and staging. The key indicator should be the time from receipt of referral to start of treatment (if carried out locally) or to onward referral (if treatment carried out elsewhere). This time should be 4 weeks or less.
• The lung cancer team should have access to adequate radiology for diagnosis and staging. Necessary techniques are plain radiology, ultrasound scanning, CT scanning and radioisotope imaging. Facilities should be available for CT guided biopsy.
• Chemotherapy should only be given by clinicians experienced in the regimens used and where adequate support staff (nursing, pharmacy) are available, in accordance with JCCO criteria. In hospitals, where oncology time is available the medical oncologist or clinical oncologist should be responsible for chemotherapy treatment.
• The lung cancer team should have access to adequate histopathology services. There should be facilities for external histopathology review of difficult cases. Consideration should be given to setting up a Welsh panel of histopathologists with expertise in particular tumour types.
• The lung cancer team should be actively involved in clinical research. This will normally be carried out in conjunction with the local cancer centre or with regional or national research programmes.
• The lung cancer team should collect data on all patients diagnosed with lung cancer in their hospital and should monitor their outcome.
• Consideration should be given to setting up a system of external review of written guidelines and the work of the team as a whole.

**Evidence base**
1. Published papers
2. Consensus in Wales
3. CSEG
Management of Skin Cancer

4.137 Skin cancers may be divided into melanomas and the more common non-melanomas. Non-melanoma skin cancer is further divided into basal cell carcinoma and squamous cell carcinoma. There has been a dramatic increase in the prevalence of all forms of skin cancer world-wide.

4.138 The majority of skin cancers are treated under local anaesthesia on an outpatient basis. There is no central database in Wales for the recording of clinical outcome following treatment by the various specialities involved.

Recommendations

Skin cancer in general

- There should be an increased emphasis on prevention and health promotion. This should include health education for both the public and primary care professionals.
- The adequacy of excision and accuracy of diagnosis should be audited by dermatopathology collaboration.

Melanoma

- Rapid access clinics should be available for pigmented lesions in which patients may be seen within two weeks of referral.
- All cases of suspected melanoma should be assessed by a consultant dermatologist prior to treatment.
- There should be a close working relationship between the dermatologist and an appropriate surgeon trained in the surgical management of melanoma.
- Melanomas should be excised by a dermatologist with the appropriate training, or by a surgeon with a special interest in melanoma. Advanced melanomas or those in anatomical sites such as the face posing reconstructive difficulties, should be referred to designated centres in which there are established melanoma groups. Such centres should be staffed by a multidisciplinary team with access to joint clinics. A melanoma group would normally consist of a dermatologist, surgeon, oncologist/radiotherapist and a histopathologist with particular expertise in the field of pigmented lesions.

Facts

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<td>1985-94</td>
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Sources:
- Wales Cancer Registry (new patients)
- West Midlands Regional Cancer Registry (survival 1984-1988)
- Healthcare Management Information Services, WHCSA (deaths)
Non-melanoma skin cancer

- Treatment will generally continue to be at district general hospital level under the direction of a dermatology department.

- Many cases of non-melanoma skin cancer will be treated by dermatologists. In addition, the dermatology unit should develop close working relationships with a surgeon trained in the management of more extensive non-melanoma skin cancer. Patients with recurrent or ill defined basal cell carcinoma may benefit from treatment in a dermatology unit with expertise in Mohs’ surgery. Many non-melanoma skin cancers will be on the face, and the treatment of the larger lesions should be carried out by surgeons with appropriate training in facial reconstruction. In the majority of cases this would be a plastic, maxillofacial or oculoplastic surgeon.

- Where there is histological evidence of complete excision of a basal cell carcinoma, there may be little need for follow-up following excision of small lesions. Where complete excision is uncertain, follow-up arrangements between primary and secondary care should be determined by local criteria.

Evidence base

1. Published papers
2. Consensus - Welsh dermatology departments
3. Consensus - dermatology, plastic surgery, maxillofacial surgery and general surgery units consulted in Wales
4. Consensus - Welsh oncology units and dermatology departments

Consensus drawn form evidence provided by those units who contributed to this task group report.
Management of Urological Cancer

Cancers of the prostate, bladder, kidney and testes are the principal urological cancers. Cancer of the prostate and bladder are the most common and usually affect people over 60 years of age and are a significant cause of morbidity. Testicular cancer is less common but is curable in nearly all men who are diagnosed early. Currently, there is no evidence that screening for prostate or bladder cancer will have any significant impact on the eventual mortality rate.

Recommendations

- All General Practitioners should have access to a service offering rapid investigation and diagnosis for patients with visible haematuria.
- All local groups should agree local protocols for the investigation of patients with prostatic symptoms. This will have two aims:
  a) To avoid unnecessary referral of patients with mild symptoms
  b) To identify patients with a high probability of a diagnosis of malignancy (abnormal digital rectal examination or abnormal PSA or both). Examples of this might be a one-stop clinic or a visiting expert service.
- All General Practitioners should have access to a surgeon with urological training and should know who provides this service in their locality.
- The guidelines on urological cancer, produced by the British Association of Urological Surgeons, should be adopted nationally, with local interpretation to fit local geography and variations in service provision.
- All cases of urological cancer should be registered with a central cancer registry, including information on diagnosis and staging, and linking this with eventual outcome measures.
- The network should audit adherence to the national guidelines on management of urological cancer.
- Access to palliative care should be available in all areas.
- It is reasonable for general surgeons with urological training (approved by the Specialist Advisory Committee in Urology or British Association of Urological Surgeons) but who are not full-time specialist urologists, to provide a service for the endoscopic control of superficial bladder cancer, the management of benign prostatic hypertrophy and the surgical management of renal cancer, provided that they comply with nationally accepted guidelines.
- There should be a multidisciplinary team holding either combined clinico-pathological meetings or combined clinics, at which major management decisions can be made on complex cases. Along with a urologist, the team should comprise a clinical oncologist, radiologist and pathologist with a special interest in urological oncology. There should be access to a clinical geneticist.
- The multidisciplinary teams should participate in audit and research.

Facts

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Average annual registration of cancers

% Patient Survival

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Sources:
- Wales Cancer Registry (new patients)
- West Midlands Regional Cancer Registry (survival 1984-1988)
- Healthcare Management Information Services, WMCSA (deaths)
• Specialised surgery for urological cancer would include radical cystectomy, radical prostatectomy, retroperitoneal lymph node dissection for testicular cancer, nephrectomy for renal cancer with IVC involvement, and reconstruction following ablative surgery. This range of surgery should only be performed in a hospital with the appropriate support and backup facilities (e.g. radiology, intensive therapy, fully trained anaesthetists, dedicated theatre and theatre team, and dedicated ward and ward staff) by surgeons who have appropriate training and experience in those techniques.

• External beam radiotherapy should be performed by appropriate site-specific oncologists with radiotherapy equipment of the highest possible standard.

Evidence base

2. Published papers
3. Consensus within Wales

Consensus is derived from the evidence submitted by those contributing to this Task Group report.
Management of Breast Cancer

A comprehensive breast service includes health promotion, screening, primary care services, a specialist breast unit and cancer registration. Screening is expected to result in a reduction in breast cancer mortality of up to 25% in the population included in the national screening programme. Further improvements in survival and reduction in breast cancer deaths can be expected to follow for women presenting symptomatically to specialist services where there is accurate diagnosis using triple assessment which informs treatment planning decisions. The sub group of the Clinical Outcomes Group have recently published standards for breast cancer services and suggest that up to 20% reduction in 5 year mortality may be expected from a specialist breast unit with a team of specialists working together.

Recommendations

- Primary health care teams should promote breast awareness and encourage appropriate screening attendance of eligible women.
- Breast Test Wales (BTW) should continue to conform to UK screening policy guidelines, to meet all national quality standards and to evaluate programme effectiveness.
- All patients with breast disease should have access to high quality care provided by a multidisciplinary team of specialists working together in a specialist breast unit.
- Each specialist breast team should consist of a core group of named breast specialists including surgeon, radiologist, pathologist, clinical oncologist, breast care nurse and radiographer. The unit should identify a lead clinician who will normally be the breast surgeon.
- The specialist breast team should have access when required to other named specialists in palliative care, psychological medicine, clinical genetics and plastic surgery, who should be affiliated members of the specialist team with appropriate supporting services.
- General Practitioners should have clearly established links with their local specialist breast unit and team.
- General Practitioners should refer women with significant breast symptoms and signs to the specialist breast unit and team. To ensure that patients are referred appropriately and seen promptly, referral policies and guidelines which meet national standards should be agreed, used and audited locally.
- Diagnosis should be based on triple assessment (clinical assessment, imaging, cytology/needle biopsy) carried out by the multidisciplinary team in a dedicated clinic held at least weekly.
- The specialist breast team should hold regular combined clinico-pathological review meetings to confirm diagnosis and to plan treatment.
- The specialist breast team should use locally agreed protocols and guidelines which cover all aspects of care.
• The specialist breast team should arrange for appropriate information, counselling and support to promote patient involvement in decisions about their management including follow-up. The breast care nurse has a key role in ensuring that patients' information needs are co-ordinated before, during and after treatment.

• Treatment and follow up for patients with breast cancer should be co-ordinated by the specialist breast team and provided in the specialist breast unit. Radiotherapy will take place in the cancer centre. If chemotherapy is to be delivered in the specialist breast unit, adequate supervision by a specialist should be available with appropriate facilities and specialist nursing support.

• To ensure efficient and timely delivery of treatment programmes, the specialist breast unit should have operational links with the local cancer centre. This arrangement should be facilitated by the specialist clinical oncologist who should have dedicated sessions at both cancer centre and specialist breast unit.

• There should be adequate facilities and services in radiology and pathology to support the specialist breast team in both the specialist breast unit and cancer centre. There should be QA systems in place to ensure that equipment and procedures meet national standards with adequate medical physics services support.

• There should be effective liaison and communication within the specialist team, with General Practitioners, patients and families.

• The specialist breast team should participate in research including multi-centre trials.

• There should be adequate data collection with appropriate personnel and IT support to facilitate clinical audit, quality assurance, patient satisfaction and outcomes.

• A critical mass of patients is needed to maintain expertise, support specialist training programmes and justify the necessary infrastructure. The minimum number of new cases of breast cancer should probably be no less than 50 per annum, but it may be more appropriate to plan for units that manage 100 new cases per annum.

• The specialist breast units should establish links with BTW.

**Evidence base**

1. NHSBSP/CRC publications
2. BTW business plan 1995 - 98.
3. British Breast Group publications
4. BASO publications
7. Audit Commission Report: What seems to be the matter?, 1993
8. Published papers
Management of Gynaecological Cancer

The prognosis of cervix, ovarian and uterine cancer is influenced by stage at presentation. In ovarian and cervical cancer, prognosis is also influenced by access to expert treatment. For ovarian cancer, chemotherapy has effected outcome since 1980’s. Optimum outcome for these cancers, appears to be determined by:

a) access to gynaecologists for early diagnosis
b) availability of expert surgery, radiotherapy and chemotherapy
c) well organised, modern specialised care

Recommendations

- Gynaecological cancer should be diagnosed by a gynaecologist following guidelines laid down by a multidisciplinary team or a gynaecological oncologist in the local cancer centre. Subsequent management will be defined according to a locally agreed multidisciplinary optimum practice protocol agreed with clinicians and purchasers.

- Once diagnosed all patients should be registered at the designated local cancer centre and referred for the opinion of a multidisciplinary gynaecological oncology team, the siting of which may reflect local circumstances.

- There should be a multidisciplinary team comprising a surgical gynaecological oncologists, a clinical or medical oncologist, a pathologist and a cancer nurse specialist. Associates, involved with selective patients include consultants in radiology, providing MRI and CT facilities, palliative care and clinical genetics.

- The surgical gynaecological oncologist and specialist pathologist should devote 50% of their time to gynaecological cancer. The clinical or medical gynaecological oncologist should have at least 3-4 dedicated sessions per week. The multidisciplinary team should deal with a minimum of 10-15 vulval cancers and 20-30 radical hysterectomies per year to ensure appropriate specialisation and training.

- The lead clinician of the multidisciplinary team should be a recognised gynaecological oncologist and should ensure the maintenance of high standards, participation in medical audit, research trials and continuing medical education.

Evidence base

3. Subspecialisation in Gynaecological Oncology (Syllabus). The Royal College of Obstetricians and Gynaecologists 1987
5. Published papers
Management of Haematological Cancer

4.142 The incidence of haematological cancers in Wales and the geographic location is precisely known as a result of an ongoing Epidemiology Study. The facilities to manage such cases have been defined by the Clinical Task Force of the British Society for Haematology and the current review has shown that the existing pattern of management of cases in Wales already achieves much of what is envisaged in the Calman/Hine report. Specialist services can be accessed in all hospitals in Wales, appropriate diagnostic facilities are available on-site, augmented by specialist laboratories at other hospitals.

Recommendations

• The registration of disease which is already undertaken by haematologists in Wales should continue and extended to non-Hodgkin’s Lymphoma and Hodgkin’s Disease.

• Established patterns of care should broadly continue with further development of shared care.

• Appropriate support should be provided to haematologists, as suits local needs, to facilitate the adoption of guidelines of care, clinical trial participation and outcome measurements. This will require extra medical sessions, provision of nurse practitioners and clerical resources.

• All individuals involved in the provision of care should be aware of their role within the multidisciplinary team. They should have access to continuous training.

• The continuing delivery of optimum care should be the responsibility of a supervisory group who are at present primarily involved in the supervision of patients with haematological malignancies. This group would be responsible for developing and implementing guidelines/protocols, brokering clinical research and devising appropriate training for staff involved in treatment delivery. This group will also develop outcome measurements and make such information available to Health Authorities, NHS Trusts Directors of Public Health Medicine and General Practitioners on an annual basis. This group will require appropriate administrative and statistical support.

• Means of communicating treatment intentions to colleagues in primary care should be improved.

Evidence base

1. All Wales Register of Haematological Malignancy: First Interim Report 1991 - 1993
2. Comprehensive Care in Leukaemia. Leukaemia and Lymphoma Forum 1994
3. Joint Haematology Committee
4. Published papers
Management of Head and Neck Cancer

Head and neck cancers cover a disparate group of cancers that differ in their cause, management and outcome. By convention, thyroid and brain cancer, are excluded from this group. 80% of head and neck cancers are squamous cell carcinomas of the upper aerodigestive tract which are often related to tobacco and alcohol consumption. The majority are therefore preventable. The treatment required varies widely between the various types of tumour, and the specialities undertaking their management vary depending on their training and anatomical area of interest.

The treatment of squamous cell carcinoma of the upper aerodigestive tract generally involves surgery, radiotherapy or a combination of the two. The role of chemotherapy is more controversial and on the basis of the evidence available should, wherever possible, be used as part of a multicentre trial. The criteria for the structure of multidisciplinary head and neck cancer teams outlined below are based in part on recommendations currently under discussion by the British Association of Head and Neck Oncologists.

Recommendations

- There are 450 - 500 new cases of head and neck cancer per year in Wales. Many are related to tobacco and alcohol abuse and are preventable. There should be an increased emphasis on prevention and health promotion. This should include health education for both the public and primary care professionals.
- Head and neck cancers are relatively rare. They should be managed in functional cancer centres under the care of a multidisciplinary team of specialists. Ideally there should be at least one ENT surgeon, one maxillofacial surgeon and/or plastic surgeon and one clinical oncologist (radiotherapist and oncologist) who has special expertise in the management of head and neck cancer.
- The head and neck cancer centre should have ITU and HDU facilities.
- The head and neck multidisciplinary cancer team should have ready access to surgical, vascular and cardiothoracic services.
- Nursing expertise should be available to the head and neck multidisciplinary cancer team and should include.
  - Ward nurses trained in head and neck oncology
  - A clinical nurse specialist
  - A palliative care nurse
  - A community liaison Nurse
- Speech therapy services should be available and a functioning voice restoration programme is essential for the treatment of cancer of the larynx.
- A head and neck multidisciplinary cancer team should have a maxillofacial laboratory for the construction of facial and oral prostheses.
- A restorative dentist should form part of the head and neck team. A dental hygienist service is also essential.
- A maxillofacial service for the construction of implant retained facial and oral prostheses should be available to the cancer centre.
- Joint multidisciplinary head and neck clinics should be held in the head and neck cancer centre at least every fortnight.
- There should be ready access to modern imaging facilities including MRI, CT, ultrasound and nuclear imaging. There should be a named radiologist with particular expertise in head and neck imaging.
- The head and neck multidisciplinary cancer team should have the services of a histopathologist with special expertise in head and neck pathology. There should be a cytopathology and frozen section service.
- A functional head and neck multidisciplinary cancer team should treat at least 80-100 new cases per year. These numbers are not based on outcome data, but are considered necessary to facilitate the provision of a full range of supporting services and to provide research and training opportunities.
- Thyroid cancer should be managed by a recognised multidisciplinary team with a specialist surgeon and a dedicated clinical oncologist. Ideally an endocrinologist should form part of the team.

Initial work has been undertaken with regard to brain and thyroid cancer however, these will be the subject of a further CSEG study.

**Evidence base**

1. Published papers
2. British Association of Head and Neck Oncologists recommendations
3. Consensus within Wales and/or the wider UK

Consensus is derived from the evidence submitted by those contributing to this task group report.
Management of Childhood Cancer

A definite survival advantage has been shown for children with cancer who are referred to specialist children’s cancer centres, and for those treated within multi-centre clinical trials. As treatment is administered to the growing and developing child, and many children are long term survivors, late effects of therapy are of major concern, and careful thought must be given during treatment to minimising both short and long term toxicity. Long term follow up to detect and treat late effects is mandatory to good quality care, and requires a multi-disciplinary team approach. Particular areas of concern are growth, pubertal development and fertility, cardiac, renal and endocrine function, and neuro development.

Recommendations

- All children with cancer should be referred to a UKCCSG centre, as early as possible once a diagnosis of malignancy is suspected. Surgery is best performed at the centre, to ensure appropriate sampling, optimum use of tissue for diagnostic and biological studies, and to avoid excessive excision with consequent late effects. Central review of pathology must be mandatory.
- Children should be treated in well-planned multi-centre clinical trials.
- Radiotherapy is best administered in the department integrated with the children’s cancer centre. The radiotherapy working party of the UKCCSG strongly recommends that children should not receive treatment in other radiotherapy departments.
- Particular attention should be paid to the needs of adolescents, with referral determined by patients’ wishes, diagnosis, and the most appropriate treatment environment for the individual’s maturity. Consideration should be given to the development of adolescent units.
- Particular consideration is required for tumours of the central nervous system. Close liaison between neuro-surgical units and the children’s cancer centre should be mandatory with a collaborative approach to care.
- Family support spanning community and hospital is essential, and each family must have an identified community nurse and social worker from the specialist multi-disciplinary team. There should be ready access to support groups, and the team should include a child psychologist. The multi-disciplinary teams should work closely with local services, particularly the PHCT, and care plans should be formulated in every case to ensure a co-ordinated approach to optimise input from all resources including the voluntary sector. In particular, palliative care requires very close liaison between the multi-disciplinary team and the PHCT. Palliative care for children in general should be developed and involved as appropriate in the care of children with cancer, although advice on symptom control falls within the remit of the specialist multi-disciplinary team.

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% New Patients by site from 1985 - 1990

- Leukaemia: 42%
- CNS: 36%
- Retinoblastoma: 18%
- Other: 4%

% Patient Survival

- Lymphomas
- Solid Tumours
- All Tumours
- Leukaemias
- Brain Tumours

Sources:
- National Registry of Childhood Tumours (*confirmed cases*)
- Wales Cancer Registry (projected new patients)
- West Midlands Regional Cancer Registry (survival 1984-1988)
- Healthcare Management Information Services, WHCSA (deaths)
• Shared care should be carefully planned, with comprehensive joint protocols, and the level of shared care practical will vary dependent on expertise and patient numbers seen within local hospitals

Evidence base
2. ‘Tertiary services for Children and Young Children’ British Paediatric Association, 1995
3. EC Committee on Paediatric Oncology ‘Paediatric oncology in Europe’. 1992
6. ‘Standards of Care for Children with Leukaemia’ Department of Health 1996
7. Discussion document circulated to the majority of provider units for children in Wales with consensus of agreement to the statements made.
8. Published papers
Appendix 1

Task Group terms of reference

Generalist

1. Task Groups, to be headed by one nominated CSEG member, must collect relevant colleagues around them as required and liaise widely with all professionals both within and without the CSEG group and professional bodies who have an interest in cancer care for patients.

2. The remit was:
   a) to describe what would be the ideal service including a definition of roles and accountability of respective members of the primary health care team and community. This should be based on following the patient through the system and backed by any available audit data, national recommendations of professional bodies, etc. The description should also:
      • comment upon future developments with respect to availability and provision of the service, manpower demand and needs for education and training.
      • take account of specialist PAMs, other professionals (e.g. pharmacists) and voluntary sector involvement.
      • not to say where services should be - just what in general they should look like.
      • suggest indicators which would be used to monitor and evaluate any recommended changes.
   b) to identify in conjunction with the Project Office and the tumour site specific task groups where the appropriate specialist services and interfaces are now, their base and outreach clinics.
   c) to identify in general current patient flows within existing health authority boundaries.

3. To report to CSEG by 31 January 1996.
**Tumour site specific**

1. Task Groups, to be headed by one nominated CSEG member, must collect relevant colleagues around them as required and liaise widely with all professionals both within and without the CSEG group and professional bodies who have an interest in cancer care for patients.

2. The remit was:
   
a) to describe what would be the ideal service for the particular tumour site(s) under review. This should be based on following the patient through the system and backed by any available audit data, national recommendations of professional bodies, etc. The description should also:
   
   • comment upon future developments with respect to availability and provision of the service, manpower demand and needs for education and training.
   
   • take account of the primary health care team, specialist PAMs and other professionals’ (e.g. pharmacists) involvement.
   
   • *not* to say *where* services should be - just what in general they should look like.
   
   • suggest indicators which would be used to monitor and evaluate any recommended changes.
   
   b) to identify in *general*, and in conjunction with the Project Office, current patient flows within existing health authority boundaries - backed with data in terms of new cases per year, preferably spanning the last five years whenever possible.
   
   c) to identify where the consultants are now, their base and outreach clinics.

3. To report to CSEG by 31 January 1996.
## Appendix 2

### CSEG members and acknowledgements

**Chairman**  
Professor IR Cameron  
Provost and Vice Chancellor, University of Wales College of Medicine

**Project Office**  
Project Manager: Dr JAV Pritchard  
Project Co-Ordinator: Dr JA Hanson  
Public Health Medicine: Dr P Donnelly

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<tr>
<th>Task Group</th>
<th>Leader</th>
<th>Details</th>
</tr>
</thead>
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<tr>
<td>Prevention &amp; Screening</td>
<td>Dr R Hall</td>
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</tr>
<tr>
<td>The Patient View</td>
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<tr>
<td>Nursing</td>
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<td></td>
<td>Sister A Davies</td>
<td>Clinical Nurse Specialist, Swansea NHS Trust</td>
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<tr>
<td>1. Palliative Care</td>
<td>Prof. IG Finlay</td>
<td>Medical Director, Holme Tower Marie Curie Centre, Cardiff</td>
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<tr>
<td>2. Quality of Life</td>
<td></td>
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</tr>
<tr>
<td>1. Information Issues</td>
<td>Prof. JG Williams</td>
<td>Consultant Gastroenterologist &amp; Director of School of Postgraduate Studies Morriston Hospital NHS Trust</td>
</tr>
<tr>
<td>2. Urological Cancer</td>
<td></td>
<td></td>
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<tr>
<td>Finance</td>
<td>Mr AF Ames</td>
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<td>Gastrointestinal Cancer</td>
<td>Mr JD Stamatakis</td>
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<td>Lung Cancer</td>
<td>Dr NAS Stuart</td>
<td>Consultant Medical Oncologist, Ysbyty Gwynedd NHS Trust</td>
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<tr>
<td>Breast Cancer</td>
<td>Dr RE Roberts</td>
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<tr>
<td>Haematological Cancer</td>
<td>Prof. AK Burnett</td>
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<tr>
<td>Gynaecological Cancer</td>
<td>Dr MA Adams</td>
<td>Medical Director and Consultant Clinical Oncologist, Velindre NHS Trust</td>
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<td>Consultant Gynaecologist, University Hospital of Wales Healthcare NHS Trust</td>
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<tr>
<td>1. Head &amp; Neck Cancer</td>
<td>Mr DW Patton</td>
<td>Consultant Maxillofacial Surgeon, Morriston NHS Trust</td>
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<tr>
<td>2. Skin Cancer</td>
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<td>Childhood Cancer</td>
<td>Dr D Webb</td>
<td>Consultant Paediatric Oncologist Haematologist Llandough Hospital &amp; Community NHS Trust</td>
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Acknowledgements

It has been very helpful to link with regional groups in England, and we particularly thank Professor Haward as Chairman of the Cancer Sub-Group of the Clinical Outcomes Group [COG], for sight of early draft documentation regarding the guidance for purchasing breast cancer services.

The Task Group leaders drew up their reports following wide consultation amongst colleagues and grateful thanks are extended to the following people or organisations:

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- Glan Hafren NHS Trust
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Dr D Shickle, Lecturer in Public Health, University of Wales College of Medicine (Epidemiological analysis)
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Superintendent Radiographers, including Mrs D Winstone at Breast Test Wales
Medical Physicists, including Ms A Burch at Breast Test Wales
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The Children's Cancer Research Group
The United Kingdom Children's Cancer Study Group
Community and Hospital Paediatricians throughout Wales
## Appendix 3

### ICD 9 codes

The following codes were selected by the Task Group Leaders and were used to obtain data of cancer incidence and mortality. Data were also extracted from the PEDW database using these codes.

<table>
<thead>
<tr>
<th>Tumour Site</th>
<th>Task Group Leader</th>
<th>ICD9 Codes</th>
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<td>Breast Cancer</td>
<td>Dr RE Roberts</td>
<td>174, 175, 233.0, 238.3</td>
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<td>Mr JD Stamatakis</td>
<td>150-157, 197.7</td>
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<td>Mr A Evans/Dr MA Adams</td>
<td>179, 180, 182, 183, 184, 233.1</td>
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<td>Haematological Cancer</td>
<td>Professor AK Burnett</td>
<td>196, 200-208</td>
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<td>Lung Cancer</td>
<td>Dr NAS Stuart</td>
<td>162, 163</td>
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<td>Childhood Cancer</td>
<td>Dr D Webb</td>
<td>&lt;15 years</td>
</tr>
<tr>
<td>Skin Cancer</td>
<td>Dr DW Patton</td>
<td>172, 173, 230.0, 232</td>
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<tr>
<td>Head &amp; Neck Cancer</td>
<td>Dr DW Patton</td>
<td>140-149, 160, 161, 170.0, 170.1, 171.0, 190, 195.0</td>
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<td>Cancers of the Central Nervous System</td>
<td>Dr DW Patton</td>
<td>191, 192</td>
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<td>Endocrine Cancer</td>
<td>Dr DW Patton</td>
<td>193, 194</td>
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<tr>
<td>Urological Cancer</td>
<td>Professor JG Williams</td>
<td>185, 186, 188, 189, 236</td>
</tr>
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Appendix 4

Definitions

This report makes recommendations regarding the working of specialists within specialist multidisciplinary clinical teams. The following have resulted from CSEG deliberations taken alongside draft documentation from The Clinical Outcomes Group (COG) sub-groups on breast and colorectal cancer.

A Specialist Multi disciplinary Cancer Team is ...

A group of specialists, working together under appropriate leadership to achieve an accurate speedy diagnosis, and decide, implement and monitor effective treatment and care as determined by locally and nationally agreed evidence-based guidelines and protocols. The team must communicate effectively with patients, professionals and within itself and audit its outcomes. Individual members must keep up-to-date in their own fields.

The team will be comprised of core and associate members. The membership will vary dependent upon the tumour site

Specialisation of core team members is defined in terms of training, experience, research and time commitment. The associate team specialisation should include a formal commitment of a named individual to the team but who is not necessarily involved in the care of all patients.

The core team will meet regularly, be properly resourced and respect the principles of effective team working. Members of the associate team attend the regular meetings as and when appropriate.

An appropriate senior clinical specialist will be designated to lead the team. He/she will provide evidence for their specialist interest as described above. He/she will be responsible for the team and an annual review of its membership, processes, patient satisfaction and clinical outcome.

The team will ensure that all those involved in the care of the patient, including the PHCT, are fully informed of the treatment plan which has been agreed with the patient

There are many means by which staff can maintain their knowledge over time for example:

- professional requirements for continuing education
- formal courses/training programmes
- distance learning
- scientific and other conferences/symposia
- peer group activities

Guidelines describe the key principles which determine the clinical management of particular cancers

Protocols provide the detail of particular treatments that follow the clinical management decisions outlined in guidelines.

The team will set aside separate times for audit. Results of audit will be published