Scottish Needs Assessment Programme

Cancer Services

in Scotland

---

1 LILYBANK GARDENS
GLASGOW G12 8RZ
Tel - 0141 330 5607
Fax - 0141 330 3687

PEOPLE CONSULTED

This report has been prepared by **Dr Charles Gillis** of the West of Scotland Cancer Surveillance Unit and **Dr Catriona Smith** of Argyll and Clyde Health Board. Many colleagues helped us. They are listed below. We particularly wish to acknowledge the information and epidemiological comment supplied by **Dr David Brewster, Dr Ann Gould and Ms Amy Sandridge** of the Scottish Cancer Intelligence Unit, ISD.

Ms Avril Blamey, Health Promotion, Greater Glasgow Health Board
Professor Ian Bouchier, Chief Scientist, Department of Health, Scottish Office
Dr Andrew Carnon, MRC Fellow, University of Glasgow
Ms Anne Clarke, Health Promotion, Argyll and Clyde Health Board
Dr Derek Cox, Shetland Health Board
Dr Jon Cresswell, Grampian Health Board
Mr Joseph Cumming, Department of Health, Scottish Office
Mr Robert Diament FRCS, Crosshouse Hospital
Dr Fiona Douglas, Medical Genetics, Yorkhill Hospital
Dr Anne Findlay, National Services Division, Common Services Agency
Professor David George, Dept of Surgery, Glasgow University
Dr Michael George, Western Isles Health Board
Dr Tim Habeshaw, Beatson Oncology Centre
Dr William Hamilton, Orkney Health Board
Professor Bob Haward, Yorkshire Cancer Organisation
Mr John Helm, Department of Health, Scottish Office
Dr Brooke Hogg, Stobhill Hospital
Mr David Hole, West of Scotland Cancer Surveillance Unit
Professor Peter Howie, Scottish Cancer Co-ordinating and Advisory Committee
Dr Sue Ibbotsen, Fife Health Board
Dr Erik Jesperson, General Practitioner, Oban
Ms Nora Jodrell, Nursing Studies, Edinburgh University
Dr Margaret Kenicer,Tayside Health Board
Dr Fergus Macbeth, Beatson Oncology Centre
Dr Elspeth Macdonald, Ayrshire and Arran Health Board
Dr Ian MacDonald, Borders Health Board
Dr Lesley MacDonald, Highland Health Board
Professor James McEwen, Dept of Public Health, Glasgow University
Dr Gillian MacIlwaine, Greater Glasgow Health Board
Dr Ian Maclean, Dumfries and Galloway Health Board
Dr Andrew Millard, Scottish Clinical Audit Resource Centre
Dr Dorothy Moir, Lanarkshire Health Board
Mr George Morris, Scottish Centre for Infection and Environmental Health
Dr Rod Muir, Forth Valley Health Board
Dr Catherine O'Donnell, West of Scotland Health Services Research Network
Dr Sheena Parker, Lothian Health
Dr Gordon Paterson, Grampian Health Board
Mrs Christina Pottinger, SIGN
Dr Lewis Reay, Argyll and Clyde Health Board
Professor Michael Steel, Medical Science, St Andrews University
Mr Patrick Sweeney, Dental Public Health, Argyll and Clyde Health Board
Ms Fiona Toal, Health Promotion, Greater Glasgow Health Board
Dr George Venters, Lanarkshire Health Board
Dr Andrew Walker, Greater Glasgow Health Board
Dr Ian Wallace, General Practitioner, Thornliebank Health Centre
Ms Jan Warner, National Co-ordinator for Screening Programmes, ISD
Dr Norman Waugh, SHPIC
Professor John Welsh, Hunters Hill Marie Curie Centre

CONTENTS

Appendix 3

Appendix 4

Appendix 5

General principles which should govern the provision of cancer care
Commissioning Cancer Services in Scotland - Scottish Cancer Co-ordinating and Advisory Committee

EXECUTIVE SUMMARY

1. Cancer incidence

Cancer is now the commonest cause of premature death in Scotland. Around 29,000 men and women have a new cancer diagnosed each year. At any time around 150,000 men and women and their families live with cancer. One in three get it. One in four die as a result of it. By the year 2005 cancer incidence in Scotland is projected to increase, reflecting the expected increase in older age groups, where the incidence of cancer is higher.

2. Common cancers

Cancer incidence in Scotland is dominated by lung cancer. The next most common in men are cancers of the colon/rectum, prostate and bladder, and in women cancers of the breast, colon/rectum and ovary.

3. Complexity of cancer

Cancer is not a single disease and treatment is often complex. Every organ in the human body can be affected. The stage of presentation for treatment varies; late presentation results in poor outcomes. There are four main modalities of treatment: surgery, chemotherapy, radiotherapy and palliative care. All clinical specialties are involved.

4. Aims of cancer services:

- Prevent cancer by tackling known underlying causes.
- Encourage early presentation and screen for precancerous and early disease.
- Provide access to prompt diagnosis.
- Provide specialist and multidisciplinary care where there is evidence of benefit.
- Support cancer patients and their carers.
- Communicate effectively with patients about the disease, its effects and treatment.

5. Prevention and early presentation

Primary prevention can target the underlying causes: around 80% of cancers relate to aspects of lifestyle such as smoking, diet, the external environment, and in a minority of cases, to genetic causes. Secondary prevention (e.g. breast and cervical screening programmes) aims to detect cancer at an early stage when prognosis is better.

6. Specialist and multidisciplinary care

There is evidence that specialist multi-disciplinary care improves survival outcome for cancers of the breast, ovary and testis, haematological and childhood malignancies. Similar evidence for other cancers is awaited.

7. Reconfiguring services

The Scottish Office issued guidance on reconfiguration of cancer services in Scotland [MEL (1996)54]. The report of the Commissioning Cancer Services Subcommittee in 1996 following on the Calman-Hine report in England and Wales emphasises the need to improve the way in which cancer services are delivered in order to reduce variations in survival and improve outcomes for patients.

This re-design of cancer services must take account of the predicted rise in incidence with age and the emerging evidence on improved treatment. Patient centred care is now the focus of services and involves measures to improve quality of life and patient satisfaction.

These improved outcomes for cancer patients will be delivered through a network of cancer centres, cancer units and primary care. The Scottish Cancer Coordinating and Advisory Committee recommend all sectors of care contribute in these settings.

8. Improving the quality of cancer care

The recently published Acute Services Review has identified the need for clinicians to work co-operatively through ‘managed clinical networks’ to improve services for patients. These networks will have to develop across the current framework of cancer centres, cancer units and primary care. Key activities will be:

- the development and implementation of local protocols for managing cancer

- prospective audit of the processes and outcomes of care to demonstrate improvement and adequate standards, and to provide the robust data on cancer services for further improvement.

RECOMMENDATIONS

GENERAL

1. Health Boards and Trusts should plan services taking account of the increasing incidence of cancer and increased age of the population.

2. Health Boards and general practitioners are urged to work with providers to find how existing cancer services meet the proposals of the Calman/Hine and SCCAC reports. There is a need to clarify: the roles of the specialist cancer specific teams in cancer units and centres; referral routes; the need for specialist cancer nursing services; patient support and other professional and technical services.

3. Health Boards and Trusts need to take account of the views of patients and carers on services for cancer and find better ways of incorporating these into service planning.

PREVENTION AND EARLY DIAGNOSIS

Health Boards should:

4. have cancer control strategies in place which take account of the many factors predisposing to cancer.

5. support health promoting activities in primary and secondary care and consistently evaluate their effectiveness.

6. ensure effective screening programmes are in place for cervical and breast cancer.

7. work with local and other authorities e.g. the Scottish Environment Protection Agency to develop strategy and plans to control environmental factors which predispose to cancer.

8. commission a service from regional genetics centres to support primary care and specifically those members of their population with a high genetic risk of breast, ovarian or colon cancer because of family history.

9. In addition to participating in health promoting activities, GPs should agree protocols with specialists for rapid referral for diagnosis and treatment. Health boards should ensure confidential facilities are available both for transmitting and receiving timeous information about patients with cancer.

PRIMARY CARE

10. The role of the general practitioner in the co-ordination of care and the strategic and operational responsibilities of local healthcare cooperatives in relation to developing the Calman/Hine model require further definition.

11. An educational programme for primary care staff on all elements of cancer control is required.

HOSPITAL CARE

12. Health boards should be involved in the development of criteria for designation as a Cancer Centre or Cancer Unit as appropriate. Where the criteria for site specific cancers are not met in particular hospitals, clinicians managing these cancers should collaborate in functional networks to provide the necessary multidisciplinary, specialist services.

13. More effective communication between professionals caring for cancer patients is required.

14. The evidence for specialised care is strongest for breast, ovarian and haematological cancers in adults, testicular cancer and the rare cancers of childhood. Patients should obtain specialised treatments from tertiary providers for these cancers.

15. Cancer surgery should only be carried out by surgeons with the requisite skills and interest in particular cancers, with appropriate non-surgical oncology, specialist palliative care, nursing, pharmacy and audit support.

16. Blood and bone marrow transplantation should continue to be provided as a tertiary service although patients requiring autologous transplants may have aftercare in a DGH.

NON-SURGICAL ONCOLOGY

17. A coordinated planned approach should be taken to the deployment of non-surgical oncologists to make optimal use of their skills.

18. Discussions should take place at health board level regarding collaboration between non-surgical oncologists and surgical and medical colleagues on the administration of chemotherapy. The rising spending on new cytotoxic drugs is of concern.

19. Managers should collaborate to ensure appropriate equipment replacement programmes to prevent ineffective equipment being used.

PALLIATIVE CARE

20. Health boards should implement their palliative care strategies to meet identified need, taking account of the Scottish Partnership Agency for Palliative and Cancer Care guidelines.

21. Training in generalist palliative care should be provided for GPs and hospital professionals treating cancer patients requiring palliative care. More specialist palliative care should be provided and integrated with primary and hospital care.

22. Relevant voluntary organisations should be fully integrated into care arrangements to ensure optimal patient support.

EDUCATION AND AUDIT

23. Nationally agreed accurate and complete cancer registration data should be collected along with data to meet the minimum data sets recommended by the SIGN guidelines where they exist to facilitate the process of prospective audit.

24. A programme of continuing professional education in medicine and professions allied to medicine is required to support the programme.

25. Planners should make representation to the Scottish Council for Postgraduate Medical Education and local postgraduate committees regarding the number of training posts in non-surgical oncology in Scotland.

RESEARCH AND DEVELOPMENT

26. Hospitals should collaborate with planners of services on the introduction of new services and treatments to optimise benefits for all patients. Health Improvement Programmes provide a mechanism for this.

27. Continuing research is required on the effects of specialisation including nursing on outcomes of cancer care.

1 INTRODUCTION

Cancer takes many forms: it affects many parts of the body, manifests itself in a large number of different ways. Its management involves all clinical specialities. Methods of diagnosis and treatment are continually developing.

This report provides an overview of cancer services for patients and populations. It is necessarily general and should be supplemented, where necessary, by more detailed assessments.

Research into the causation of and treatment for cancer has been underway for many years. More recently attention has been drawn to the way in which cancer services are delivered in a number of documents and reports:

1. A Policy Framework for Commissioning Cancer Services in England and Wales (the Calman-Hine Report)[1] in April 1995,
2. the Report of the Commissioning Cancer Services Sub-Committee of the Scottish Cancer Co-ordinating and Advisory Committee (SCCAC) [2] in April 1996, and
3. accumulating published evidence on the effect of specialisation on survival outcome.

This report examines:

- the cancer burden in Scotland
- prevention and early diagnosis
- the evidence for health gain in cancer care
- service specification for cancer care
- quality assurance for cancer care
- recommendations for planning cancer services

1.2 EXPERIENCE IN ENGLAND AND WALES AND BEYOND

In England and Wales implementation of the Calman-Hine Report has begun. In some other parts of Europe similar activity has occurred. Each of the Scandinavian countries organise services in ways similar to that described in Calman-Hine. Sweden took a lead in 1974 when the Minister of Health introduced a care programme for cancer. Guidelines on the treatment of breast cancer have been in use in Denmark since 1977. In Holland there is a system of cancer centres which have defined relationships with other hospitals. Other European countries have parts of such systems in place as do the United States.

1.3 CANCER SERVICES IN SCOTLAND: CURRENT POSITION

In Scotland cancer patients are treated in almost all district general and teaching hospitals. The Croom report[3] of 1979 recommended the establishment of specialist non-surgical oncology in five locations: West Glasgow Hospitals University NHS Trust, Western General Hospitals NHS Trust in Edinburgh, Dundee Teaching Hospitals NHS Trust, Aberdeen Royal Hospitals NHS Trust and Raigmore Hospital NHS Trust in Inverness. Radiotherapy is provided only on these sites, but specialists provide outpatient services and advice to clinicians in other teaching and district general hospitals, and outreach services to rural areas. The Pringle report[4] of 1992 drew attention to the importance of specialist care and clinical audit.

Specialist care

In most areas, certain clinicians have been recognised as specialists in different aspects of cancer care. However there has been no explicit designation of specialists, with the exception of recently appointed consultants trained in recognised postgraduate programmes, nor any system of accreditation of specialist cancer units and centres.

Clinical guidelines

National clinical guidelines and local clinical protocols are in use in some parts of the country, particularly for the treatment of common cancers. Many of these have been published by specialist societies, more recently evidence based national clinical guidelines for some cancers have been published. The first to be published was the CRAG guideline *Management of Ovarian Cancer*[5] while the Scottish Intercollegiate Guideline Network (SIGN), has published *Palliative Radiotherapy for Non Small Cell Lung Cancer*[6], *Colorectal Cancer*[7] and *Breast Cancer in Women*[8].

Recommendations for Cancer Services in Scotland have been published in the SCCAC Report which reflects recommendations of the Calman-Hine report. The present report has been completed in the light of these reports, the principles of which are set out in Appendix 5.

References

1. Expert Advisory Group on Cancer (1995). A Policy Framework for Commissioning Cancer Services. Department of Health and Welsh Office.
2. Scottish Cancer Co-ordinating and Advisory Committee (1996). Report of Commissioning Cancer Services Sub-Committee. Scottish Office Department of Health.
3. Terminal Care (1979), ed Doyle D.. Churchill Livingston, Edinburgh.
4. Management of non-surgical cancer services in Scotland: a report by a Working Group set up jointly by the Clinical Resource and Audit Group and the Scottish Health Management Efficiency Group (1992). Scottish Office, Edinburgh.
5. Clinical Resource and Audit Group (1995). Management of Ovarian Cancer. Scottish Office Department of Health.
6. Scottish Intercollegiate Guidelines Network (1996). The Use of Palliative Radiotherapy in the Treatment of Non Small Cell Lung Cancer. Royal College of Physicians, Edinburgh.
7. Scottish Intercollegiate Guidelines Network (1997). Colorectal Cancer. Royal College of Physicians, Edinburgh.
8. Scottish Intercollegiate Guidelines Network (1998). Breast Cancer in Women. Royal College of Physicians, Edinburgh.

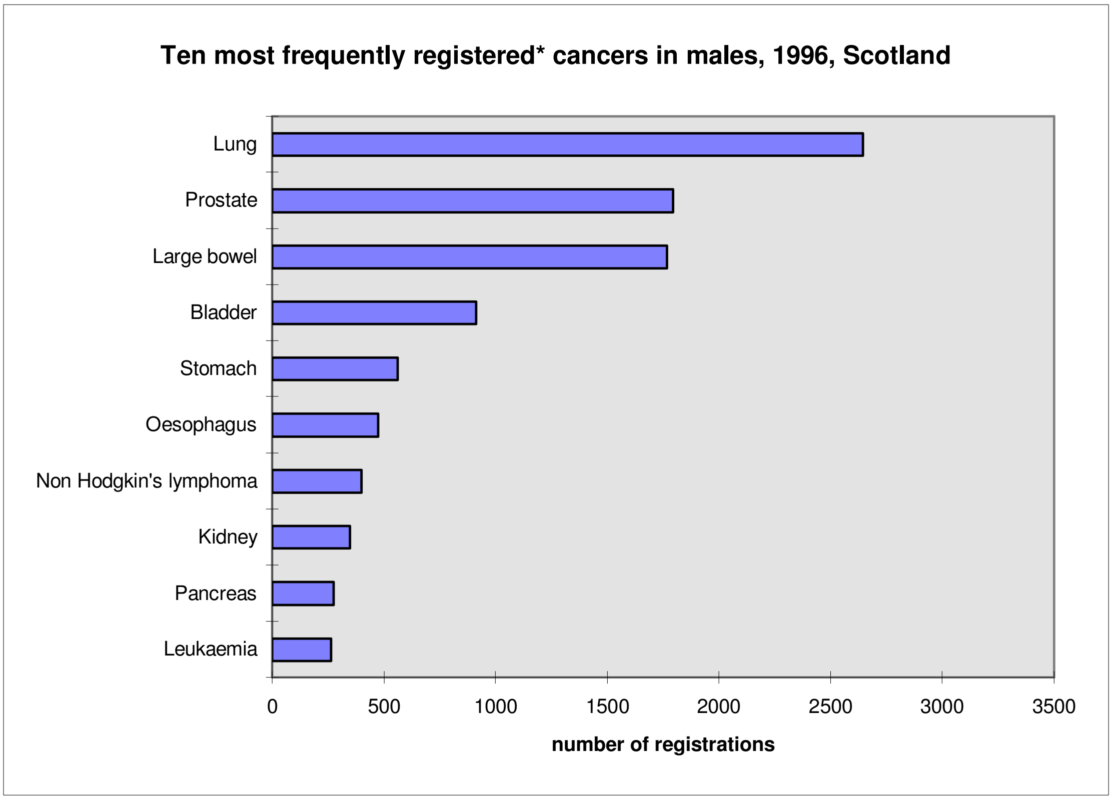
2 CANCER IN SCOTLAND

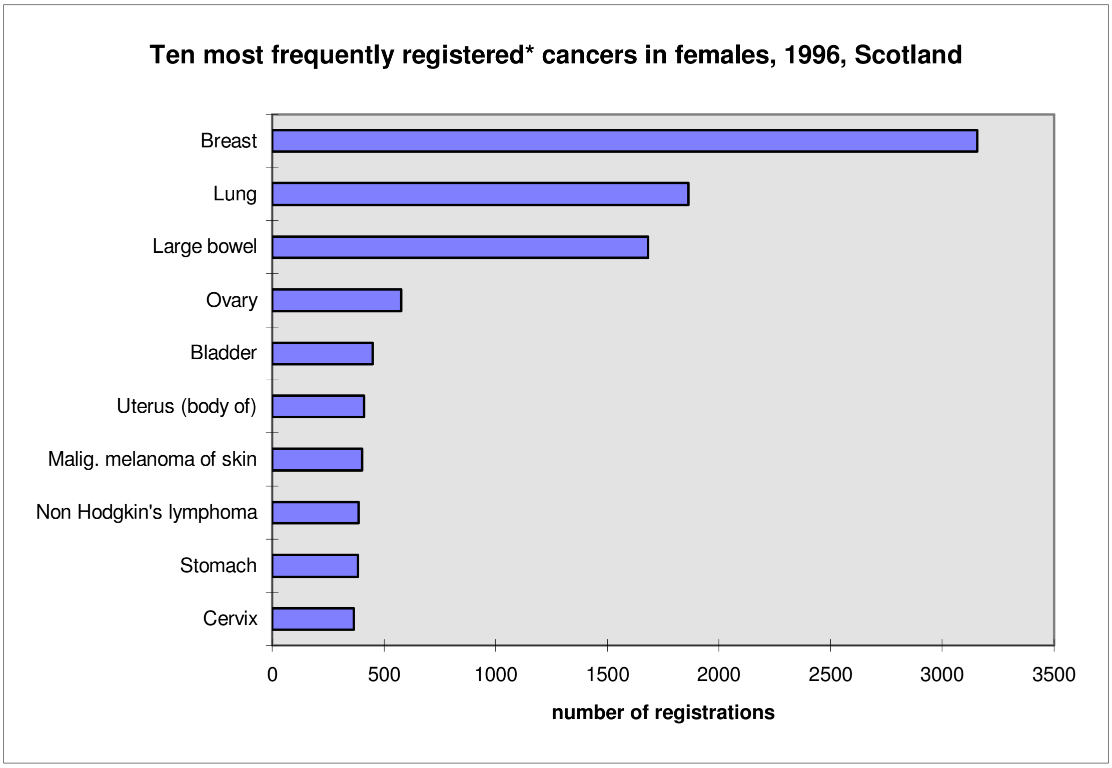
2.1 CANCER INCIDENCE AND MORTALITY

One in three of us will develop cancer at some time in our lives, and one in four will die of it. Cancer is now the most commonest cause of premature death in Scotland. Each year in Scotland 29,000 people will have a new cancer diagnosed and at any one time around 150,000 people may be affected. This number will increase towards the end of the century due to the increase in the elderly population.

The ten most frequently diagnosed cancers in Scotland for males and females in 1996 are shown in Figure 1.

Figure 1.

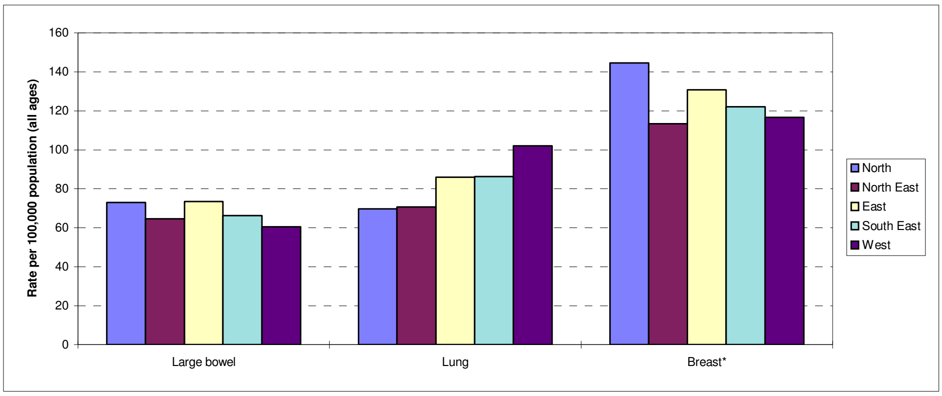




*excludes non-melanoma skin cancer (ICD9 173)

Figure 2 shows the incidence of the three most common cancers (excluding skin cancer) in the five cancer centre regions in Scotland. The numbers of these cancers by health board are given in Table 1.

Figure 2.
Cancers of the large bowel (ICD9 153+154), lung (ICD9 162) and female breast* (ICD9 174), 1992-1996.
All-ages (crude) incidence rates per 100,000 person-years at risk, by Five Cancer Centre Regions



*based on populations for females only

Region	Health Board(s)
North	Highland, Western Isles
North East	Grampian, Orkney, Shetland
East	Tayside
South East	Borders, Fife, Lothian
West	Argyll & Clyde, Ayrshire & Arran, Dumfries & Galloway, Forth Valley, Greater Glasgow, Lanarkshire

crude (all ages) incidence rates per 100,000 person-years, 1992-1996 inclusive

	Region					
	North	North East	East	South East	West	Scotland
Large bowe	73.0	64.5	73.6	66.4	60.6	64.0
Lung	69.6	70.7	86.0	86.2	102.1	92.1
Breast*	144.5	113.3	130.8	122.0	116.9	120.0

Table 1
Total number of registrations of large bowel (ICD9 153+154), lung (ICD9 162) and breast (ICD9 174) cancer, all ages, by health board area of residence, 1992-1996

	Health Board															
Site	**A&C**	**A&A**	**B**	**D&G**	**Fife**	**FV**	**Grampian**	**GG**	**High**	**Lanark**	**Loth**	**Ork**	**Shet**	**Tay**	**WI**	**Scotland**
Large bowel	1403	1145	448	526	1140	817	1715	3001	758	1314	2446	52	78	1453	106	16402
Lung	2194	1672	429	670	1464	1192	1902	5773	708	2320	3346	58	63	1697	116	23604
Breast	1342	1223	360	473	1029	850	1516	2762	742	1545	2433	58	65	1338	127	15863

Key to Health Board abbreviations:

		High	Highland
A&C	Argyll & Clyde	Lanark	Lanarkshire
A&A	Ayrshire & Arran	Loth	Lothian
B	Borders	Ork	Orkney
D&G	Dumfries & Galloway	Shet	Shetland
FV	Forth Valley	Tay	Tayside
GG	Greater Glasgow	WI	Western Isles

Table 2 shows the mean annual registrations and crude rates of cancer in children aged 0-14 years. The incidence of childhood leukaemia by health board is shown in Table 3.

Table 2
Incidence of cancer in children aged 0-14 in Scotland 1992-1996:
mean annual numbers of registrations and overall (crude) rate per 100,000 person-years at risk

Males and Females	**Mean annual number of cases registered**	**Mean annual crude rate per 100,000**
Bone and connective tissue (ICD9 170+171)	12	1.2
Kidney (ICD9 189)	7	0.7
Brain and other CNS (ICD9 191+192)	27	2.8
Non-Hodgkin's lymphoma (ICD9 200+202)	9	0.9
Hodgkin's lymphoma (ICD9 201)	5	0.5
Leukaemia (ICD9 204-208)	41	4.2
Neuroblastoma and ganglioneuroblastoma* (ICD-O M-949	9	0.9
Retinoblastoma (ICD-O M-9510 to M-9512)	2	0.2
Other neoplasms	14	1.5
All neoplasms (ICD9 140-208)	127	13.1

Table 3
Incidence of childhood leukaemia (ICD9 204-208) by health board area of residence, 1992-1996
Numbers of registrations by 5 year age group, with crude and truncated age-standardised rates per 100,000 person-years at risk (ages 0-14; European standard population), and standardised incidence ratios (with 95% CI).

	Health Board															
Registrations	**A&C**	**A&A**	**B**	**D&G**	**Fife**	**FV**	**Gram**	**GG**	**High**	**Lan**	**Loth**	**Ork**	**Shet**	**Tay**	**WI**	**S**
Under 5	12	11	3	2	8	7	7	23	7	11	19	0	2	8	1	121
5-9	4	7	0	0	4	1	4	6	4	4	7	1	0	4	0	46
10-14	6	3	1	1	2	2	2	7	3	6	3	0	0	2	0	38
0-14 total	22	21	4	3	14	10	13	36	14	21	29	1	2	14	1	205
Crude rate	5.3	5.8	4.2	2.2	4.1	3.9	2.6	4.2	6.8	3.7	4.3	5.0	8.1	3.9	3.5	4.2
trunc. EASR	5.4	6.0	4.5	2.3	4.3	4.1	2.6	4.3	7.1	3.9	4.4	4.7	8.8	4.0	4.3	4.4
SIR	124.9	137.8	100.80	52.5	99.0	92.2	60.7	98.0	163.2	89.5	99.9	120.1	190.8	91.9	86.7	100
lower 95% CI	78.3	85.3	27.4	10.8	54.0	44.3	32.3	68.3	89.1	55.4	66.9	3.0	23.1	50.2	2.2	
upper 95% CI	188.7	210.8	258.1	153.2	166.3	169.7	103.8	136.3	274.1	137.0	143.8	668.9	688.8	154.4	482.9	

Key to Health Board abbreviations:

		High	Highland
A&C	Argyll & Clyde	Lanark	Lanarkshire
A&A	Ayrshire & Arran	Loth	Lothian
B	Borders	Ork	Orkney
D&G	Dumfries & Galloway	Shet	Shetland
FV	Forth Valley	Tay	Tayside
GG	Greater Glasgow	WI	Western Isles
	Scotland	S	

The mean annual registrations and deaths for the major cancers in 1992 to1996 by health board are shown in Appendix 1.

2.2 RECENT TRENDS IN INCIDENCE OF AND MORTALITY FROM MAJOR SITES OF CANCER IN SCOTLAND

Recent trends in incidence and mortality have been summarised by reporting the percentage change in cancer incidence rates during the ten year period 1984-1993. These estimates were derived by fitting linear regression lines to each series of data. Trends in five year relative survival were taken from *Trends in Cancer Survival in Scotland 1968 - 1990*.[1]

Trachea, bronchus and lung (ICD-9 162)

Incidence The majority of lung cancers are attributable to tobacco. Other risk factors include exposure to asbestos, arsenic, chloromethyl (pyriline) ethers, polycyclic aromatic hydrocarbons, chromium products, nickel and ionizing radiation.[2] Between 1984 and 1993, the age standardised incidence of lung cancer fell by 18.1% in men and rose by 15% in women, in keeping with what is known about sex differences in historical patterns of smoking. In the city of Glasgow, lung cancer has overtaken breast cancer to become the highest incident cancer in women.[3]

Mortality During the same period, the age standardised mortality from lung cancer fell by 15.1% in males but rose by 16.6% in females. For all age groups and both sexes combined, five year relative survival has remained fairly static between the periods 1968-1972 (8.3%) and 1983-1987 (6.6%).[1]

Figure 3 shows trends in incidence and survival for lung cancer in Scotland from 1980 to 1996.

Figure 3.
Summary trends in incidence and mortality for lung cancer (ICD9 162); numbers of registrations and deaths; by year and sex, 1980-1996.

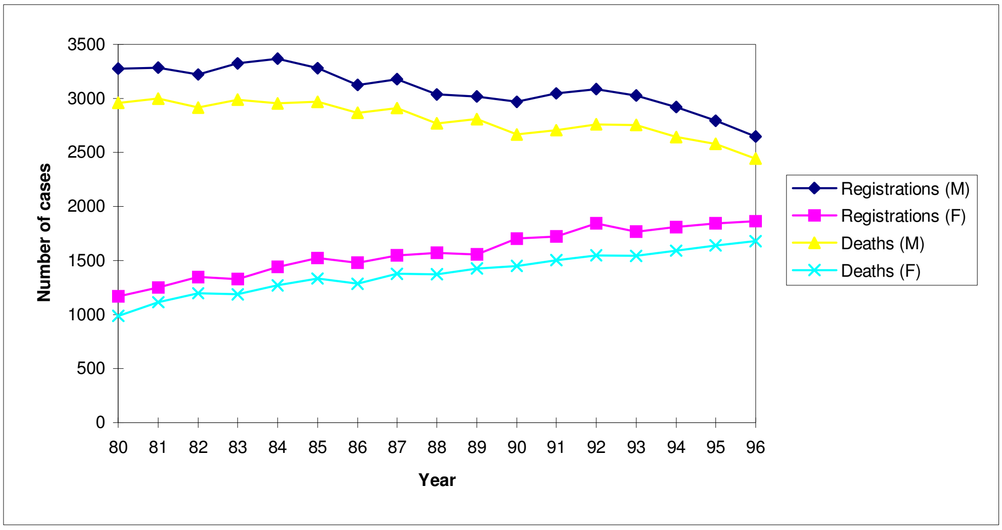


Table 4 shows international comparisons of incidence for cancer of the lung.

Table 4
Cancer of the lung (ICD9 162). International comparisons of incidence rates
Age-standardised incidence rates per 100,000 person-years at risk (World standard population) for selected countries or registries; ranked; by sex: period 1988-92

Males	Rate	Females	Rate
Scotland	**79.8**	US, SEER: White	33.8
Netherlands (1989-1992)	73.0	**Scotland**	**33.8**
Germany, Saarland	70.9	Denmark	25.4
France, Bas-Rhin	67.4	England and Wales (1988-1990)	22.8
Singapore: Chinese	62.7	Singapore: Chinese	19.6
England and Wales (1988-1990)	62.4	New Zealand: Non-Maori	18.2
Switzerland, Vaud	61.4	Australia, Victoria	15.8
US, SEER: White	61.3	Netherlands (1989-1992)	13.0
Finland (1987-1992)	54.3	Norway	12.6
Denmark	51.9	Switzerland, Vaud	12.5
Spain, Zaragoza (1986-1990)	48.0	Japan, Osaka	12.4
New Zealand: Non-Maori	46.5	Sweden	10.9
Australia, Victoria	46.0	Germany, Saarland	10.3
Japan, Osaka	43.5	Finland (1987-1992)	8.2
Norway	34.3	France, Bas-Rhin	7.2
Sweden	23.9	Spain, Zaragoza (1986-1990)	2.7

Source data for table: Cancer Incidence in Five Continents, Vol VII.
This table also appears in *Cancer Registration Statistics Scotland 1986-1995*, ISD Scotland, 1998.

Female breast (ICD-9 174)

Incidence Most of the known risk factors for breast cancer relate to a woman's reproductive history, and exogenous hormones, particularly oestrogen, probably have an important role in the development of breast cancer.[4] Only about 5% of breast cancer is due to highly penetrant dominant genes.[5] Between 1984 and 1993, the age standardised incidence of female breast cancer rose by 31%. Part of the increase in incidence can be accounted for by the introduction of the breast screening programme.[6,7]

Mortality During the same period, the age standardised mortality from breast cancer fell by 6%. This decline in mortality is also being observed in England and Wales and may be at least partly due to improvements in treatment.[6,7] It is thought to have occurred too soon to be a direct result of the national breast screening programme. For patients of all age groups, five year relative survival has improved from 56.4% for patients diagnosed during the period 1968-1972 to 64.3% for patients diagnosed during 1983-1987.[1]

Figure 4 shows trends in incidence and survival for cancer of the female breast in Scotland from 1980 to 1996.

Figure 4.
Summary trends in incidence and mortality for female breast cancer (ICD9 174); numbers of registrations and deaths; by year, 1980-1996.

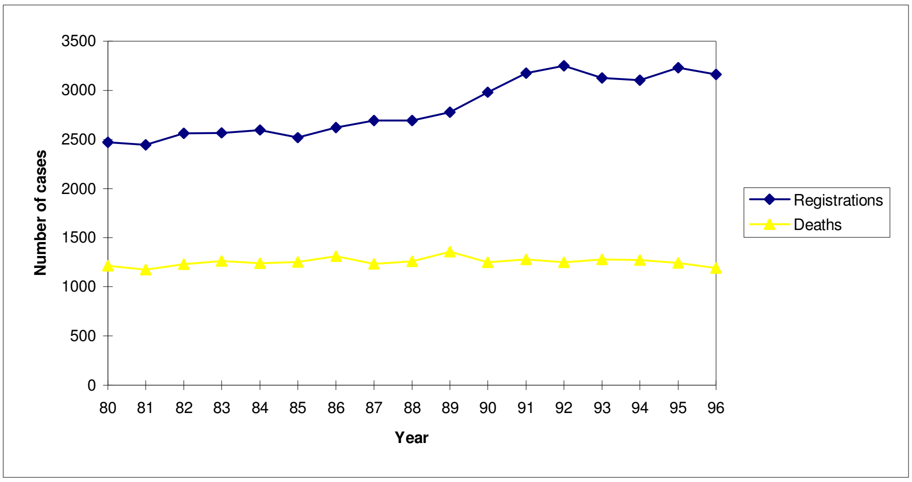


Table 5 shows international comparisons of incidence for cancer of the female breast.

Table 5
Cancer of the female breast (ICD9 174). International comparisons of incidence rates
Age-standardised incidence rates per 100,000 person-years at risk (World standard population) for selected countries or registries; ranked: period 1988-92

	Rate
US, SEER: White	90.7
Netherlands (1989-1992)	79.6
France, Bas-Rhin	78.8
New Zealand: Non-Maori	77.2
Switzerland, Vaud	77.2
Denmark	73.3
Sweden	72.9
Scotland	**72.7**
England and Wales (1988-1990)	68.8
Australia, Victoria	66.7
Finland (1987-1992)	65.0
Germany, Saarland	61.5
Norway	54.2
Spain, Zaragoza (1986-1990)	40.4
Singapore: Chinese	39.5
Japan, Osaka	24.3

Source data for table: Cancer Incidence in Five Continents, Vol VII.
This table also appears in *Cancer Registration Statistics Scotland 1986-1995*, ISD Scotland, 1998.

Large bowel (ICD-9 153 and 154)

Incidence Dietary and genetic factors appear to be the most important aetiological influences on the development of large bowel cancer.[2] Between 1984 and 1993, the age standardised incidence of colon cancer rose by 18% in men and by 6.1% in women. During the same time period, the age standardised incidence of rectal cancer rose by 18.4% in men and by 0.1% in women. It has been speculated that hormonal factors may account for the differing trends seen in men and women, although evidence from analytical studies is conflicting .[8]

Mortality During the same period, the age standardised mortality from colon cancer rose by 1.8% in males but fell by 8.8% in females. Similarly, for rectal cancer, the mortality rates rose by 7.6% in males but fell by 10.8% in females. For all age groups and both sexes combined, five year relative survival from large bowel cancer rose from 33.1% for patients diagnosed during the period 1968-1972 to 39.6% for patients diagnosed during 1983-1987.[1]

Figure 5 shows trends in incidence and survival for large bowel cancer in Scotland from 1980 to 1996.

Figure 5.
Summary trends in incidence and mortality for large bowel cancer (ICD9 153+154); numbers of registrations and deaths; by year, 1980-1996.

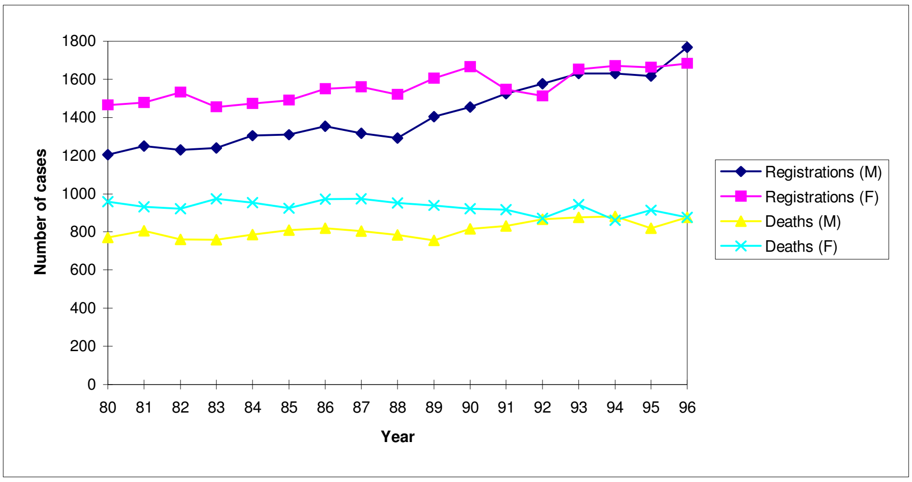


Table 6 shows international comparisons of incidence for cancer of the large bowel.

Table 6
Cancer of the large bowel (ICD9 153+154). International comparisons of incidence rates
Age-standardised incidence rates per 100,000 person-years at risk (World standard population) for selected countries or registries; ranked; by sex: period 1988-92

Males	Rate	Females	Rate
New Zealand: Non-Maori	51.3	New Zealand: Non-Maori	40.8
France, Bas-Rhin	49.2	Australia, Victoria	33.9
Australia, Victoria	46.7	Germany, Saarland	31.4
Germany, Saarland	42.8	Singapore: Chinese	31.2
US, SEER: White	42.4	Denmark	30.3
Singapore: Chinese	42.2	US, SEER: White	29.5
Scotland	**38.0**	Norway	29.4
Norway	38.0	Netherlands (1989-1992)	27.8
Denmark	37.7	France, Bas-Rhin	27.7
Netherlands (1989-1992)	36.4	**Scotland**	**27.7**
Japan, Osaka	34.2	Sweden	24.1
Switzerland, Vaud	34.0	England and Wales (1988-1990)	23.7
England and Wales (1988-1990)	33.9	Switzerland, Vaud	22.8
Sweden	29.8	Japan, Osaka	19.9
Spain, Zaragoza (1986-1990)	24.1	Finland (1987-1992)	18.2
Finland (1987-1992)	23.3	Spain, Zaragoza (1986-1990)	16.6

Source data for table: Cancer Incidence in Five Continents, Vol VII.
This table also appears in *Cancer Registration Statistics Scotland 1986-1995*, ISD Scotland, 1998.

Figure 6 shows trends in incidence and survival for cancer of the rectum in Scotland from 1980 to 1996.

Figure 6.
Summary trends in incidence and mortality for rectal cancer (ICD9 154); numbers of registrations and deaths; by year, 1980-1996.

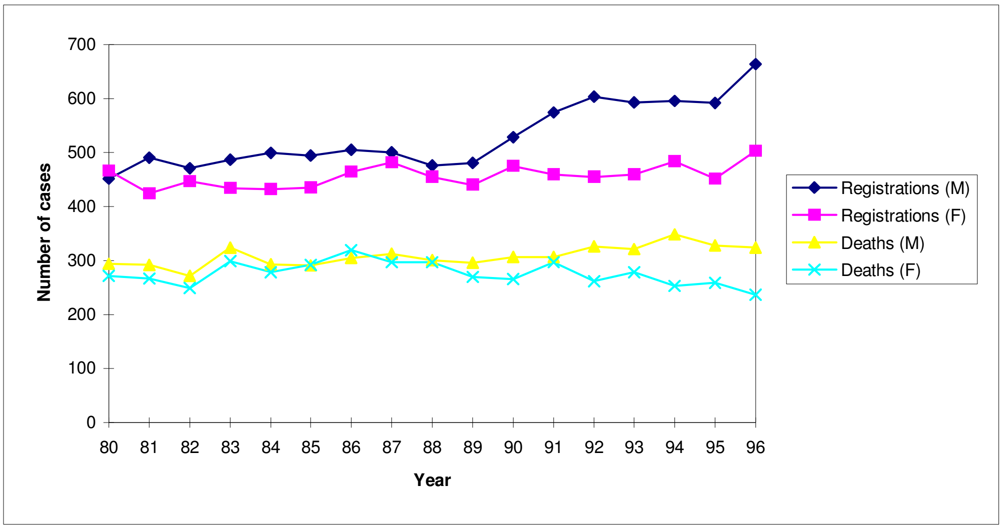


Table 7 shows international comparisons of incidence for cancer of the rectum.

Table 7
Cancer of the rectum (ICD9 154). International comparisons of incidence rates
Age-standardised incidence rates per 100,000 person-years at risk (World standard population) for selected countries or registries; ranked; by sex: period 1988-92

Males	Rate	Females	Rate
New Zealand: Non-Maori	20.1	New Zealand: Non-Maori	11.2
Australia, Victoria	19.2	Australia, Victoria	11.0
France, Bas-Rhin	19.0	Germany, Saarland	10.9
Singapore: Chinese	18.0	Denmark	10.4
Germany, Saarland	17.3	Norway	10.3
Denmark	17.0	Singapore: Chinese	10.3
Norway	15.7	France, Bas-Rhin	8.9
England and Wales (1988-1990)	14.6	Netherlands (1989-1992)	8.9
Netherlands (1989-1992)	14.5	US, SEER: White	8.7
US, SEER: White	14.3	Switzerland, Vaud	8.6
Scotland	**14.3**	**Scotland**	**8.3**
Japan, Osaka	13.5	Sweden	8.3
Switzerland, Vaud	12.3	England and Wales (1988-1990)	8.1
Sweden	12.1	Japan, Osaka	6.9
Spain, Zaragoza (1986-1990)	11.1	Finland (1987-1992)	6.6
Finland (1987-1992)	10.5	Spain, Zaragoza (1986-1990)	6.4

Source data from Cancer Incidence in Five Continents, Vol

This table also appears in *Cancer Registration Statistics Scotland 1986-1995*, ISD Scotland, 1998.

Prostate (ICD-9 185)

Incidence Causes of prostate cancer are essentially unknown.[2] The interpretation of time trends is complicated by changes in the rates of registration of latent cancers, discovered incidentally at resection or autopsy. Between 1984 and 1993, the age standardised incidence of prostate cancer rose by 32%.

Mortality During the same period, the age standardised mortality from prostate cancer rose by 30.1%. For patients of all age groups, five year relative survival has risen from 44% for patients diagnosed during the period 1968-1972 to 46.7% for patients diagnosed during 1983-1987.[1]

Bladder (ICD-9 188)
Incidence Although many potential risk factors have been studied, in this country probably 40-50% of bladder cancers are related to smoking and a smaller proportion to occupational factors.[2] Between 1984 and 1993, the age standardised incidence of bladder cancer rose by 2.4% in men and by 8.9% in women.
Mortality During the same period, the age standardised mortality from bladder cancer rose by 5.1% in males and by 14.4% in females. For all age groups and both sexes combined, five year relative survival rose from 52.8% for patients diagnosed during the period 1968-1972 to 63.5% for patients diagnosed during 1983-1987.[1]

Stomach (ICD-9 151)
Incidence Large differences in incidence between populations suggest that exogenous factors, especially diet, may be important in the aetiology of stomach cancer.[2] Recent research has also identified the bacterium, *Helicobacter pylori* as a possible risk factor.[9] In keeping with trends in other countries, between 1984 and 1993, the age standardised incidence of stomach cancer fell by 24.4% in men and by 36.7% in women. The divergent trends in oesophagus and stomach cancer are unlikely to be accounted for solely by diagnostic misclassification between tumours of the lower third of oesophagus and tumours of the cardia of stomach.
Mortality During the same period, the age standardised mortality from stomach cancer fell by 23.2% in males and by 37.8% in females. For all age groups and both sexes combined, five year relative survival rose from 8% for patients diagnosed during the period 1968-1972 to 10.6% for patients diagnosed during 1983-1987.[1]

Ovary (ICD-9 183)
Incidence Reproductive factors, such as nulliparity, and endogenous and exogenous steroid hormones appear to be important in the aetiology of ovarian cancer.[2] Between 1984 and 1993, the age standardised incidence of ovarian cancer fell by 3%.
Mortality During the same period, the age standardised mortality from ovarian cancer rose marginally by 0.5%. For patients of all age groups, five year relative survival has risen from 26.1% for patients diagnosed during the period 1968-1972 to 29.4% for patients diagnosed during 1983-1987.[1]

Oesophagus (ICD-9 150)
Incidence The main risk factors identified for oesophageal cancer are alcohol and tobacco which may interact in a multiplicative fashion.[2] Between 1984 and 1993, the age standardised incidence of oesophageal cancer rose by 36.4% in men and by 44.5% in women.
Mortality During the same period, the age standardised mortality from oesophageal cancer rose by 24.3% in males and by 29.5% in females. For all age groups and both sexes combined, five year relative survival improved little between the periods 1968-1972 (6.6%) and 1983-1987 (7.1%).[1]

Non-Hodgkin's lymphoma (ICD-9 200 and 202)
Incidence This is a disparate group of diseases and major changes in classification have occurred since the introduction of ICD-9. Immunodeficiency, chemicals and viruses have been studied as potential risk factors, but in most cases the causes remain unknown.[2] Between 1984 and 1993, the age standardised incidence of Non-Hodgkin's lymphoma rose by 26.9% in men and by 23.9% in women.

Mortality During the same period, the age standardised mortality from Non-Hodgkin's lymphoma rose by 10.3% in males and by 31.8% in females. For patients of all age groups and both sexes combined, five year relative survival rose from 33.9% for patients diagnosed during the period 1968-1972 to 43.3% for patients diagnosed during 1983-1987.[1]

Corpus uteri (ICD-9 182)

Incidence Body mass and exogenous oestrogen use are the main determinants of endometrial cancer risk.[2] Between 1984 and 1993, the age standardised incidence of endometrial cancer fell by 12.3%.

Mortality During the same period, the age standardised mortality from endometrial cancer fell by 33.6%. For patients of all age groups, five year relative survival has risen slightly from 69% for patients diagnosed during the period 1968-1972 to 71.2% for patients diagnosed during 1983-1987.[1]

Kidney (ICD-9 189)

Incidence A significant proportion of renal adenocarcinomas and cancers of the renal pelvis are associated with environmental exposures of which the most important identified so far is tobacco.[2] Between 1984 and 1993, the age standardised incidence of kidney cancer rose by 10.5% in men and by 20.1% in women.

Mortality During the same period, the age standardised mortality from kidney cancer fell by 5.9% in males but rose by 21% in females. For patients of all age groups and both sexes combined, five year relative survival has risen slightly from 32.9% for patients diagnosed during the period 1968-1972 to 35.3% for patients diagnosed during 1983-1987.[1]

Cervix (ICD-9 180)

Incidence Accumulating evidence suggests that a sexually transmitted agent (human papilloma virus) may be a major cause of cervical cancer.[2] Between 1984 and 1993, the age standardised incidence of cervical cancer fell by 16.4%. At least part of this decline could be accounted for by the cervical screening programme.

Mortality During the same period, the age standardised mortality from cervical cancer fell by 28.3%. For patients of all age groups, five year relative survival has risen slightly from 55.1% for patients diagnosed during the period 1968-1972 to 58.7% for patients diagnosed during 1983-1987.[1]

Larynx (ICD-9 161)

Incidence Smoking and alcohol account for 80-90% of laryngeal cancer.[2] Between 1984 and 1993, the age standardised incidence of laryngeal cancer rose by 26.6% in men and by 9.1% in women.

Mortality During the same period, the age standardised mortality from laryngeal cancer rose by 25.2% in males and by 42% in females. For all age groups and both sexes combined, five year relative survival rose from 60.6% for patients diagnosed during the period 1968-1972 to 65.9% for patients diagnosed during 1983-1987.[1]

Pancreas (ICD-9 157)

Incidence Tobacco is the most important aetiological factor so far identified.[2] Between 1984 and 1993, the age standardised incidence of pancreatic cancer fell by 13% in men and by 12.9% in women.

Mortality During the same period, the age standardised mortality from pancreatic cancer fell by 1.5% in males and by 5.9% in females. For all age groups and both sexes combined, five year relative survival has remained fairly static between the periods 1968-1972 (5.2%) and 1983-1987 (4%).[1]

Oral and pharyngeal cancer (ICD-9 140-149)
Incidence When considered as individual ICD codes, the incidence of malignant neoplasms in and around the oral cavity may appear low. However there are approximately 500 new cases of oral cancer each year. Approximately 85% are in individuals over 50 years. Since the early 1970s, oral cancer incidence and mortality have been increasing, and it has become apparent that these increases are most marked in the younger age groups. The incidence and mortality are higher in Scotland than in England and Wales.
Mortality The death:registration ratio indicates a mortality comparable to that of breast cancer and cervical cancer, and greater than that of melanoma. Five year survival rates vary according to the particular anatomical site, but overall have shown little by way of improvement during the last three decades. Treatment of early lesions results in improved survival and allows more conservative treatment. However most cases continue to present with advanced disease.[10]

Malignant melanoma of skin (ICD-9 172)
Incidence The majority of malignant melanomas are believed to be due to sunlight and hereditary susceptibility.[2] Between 1984 and 1993, the age standardised incidence of malignant melanoma rose by 53.7% in men and by 24% in women.
Mortality During the same period, the age standardised mortality from malignant melanoma rose by 23.2% in males but fell by 19.7% in females. For males of all age groups, five year relative survival has improved from 50.1% for patients diagnosed during the period 1968-1972 to 65.6% for patients diagnosed during 1983-1987. The prognosis for female patients is somewhat better, with survival rates having risen from 71.3% to 85.1% over an equivalent time period.[1]

Non-melanoma skin cancer (ICD-9 173)
Incidence These neoplasms, principally basal cell carcinomas and squamous cell carcinomas, are common but rarely fatal. The majority are attributable to sunlight although immunosuppression may act as a promoting factor.[2] Ascertainment of cases by the registration system is believed to be less complete than for other sites. However, between 1984 and 1993, the age standardised incidence of non-melanoma skin cancer rose by 60.5% in men and by 63.2% in women.

Further detail on the epidemiology of these and other cancers can be found in Cancer Registration Statistics Scotland 1986-1995. [11]

2.3 PROJECTED CANCER INCIDENCE BY THE YEAR 2005

Projected incidence for cancers of the lung, breast and large bowel are shown in Table 8. These were calculated using two different methods and the actual incidence in 1996. Method 1 assumes that incidence rates will remain the same in 2005 as at present, while method 2 assumes that trends in incidence rates which have been seen over the past 10 years will continue over the next 10 years. The full tables are in Appendix 2.

Table 8 Projected incidence of selected cancers in 2005

Cancer site	Males		Females	
	% change method 1	% change method 2	% change method 1	% change method 2

Lung	15%	-2%	0%	33%
Breast	-	-	4%	13%
Large bowel	4%	37%	2%	9%

For years which are already past, cancer incidence may be measured by counting the numbers of registrations. The only limitation on the accuracy of the measure is the completeness and accuracy of the registration process. However it is difficult to measure exactly the incidence of cancer in the future. It is dependent both on the size and structure of the population, and on age and sex specific incidence rates at that time. Both population and rates may be expected to continue to change. Future changes may however be estimated using known trends, but the estimates will tend to become more uncertain the further into the future that one is trying to project. Incidence projections will vary according to what assumptions are made about these changes in populations and in incidence rates.

Population projections for the year 2005 are supplied by the General Register Office for Scotland, and are calculated by the Government Actuary. They are based on the 1996 population estimates, and make assumptions about what the changes in fertility rates, mortality rates and migration rates will be over the next 10 years. These assumptions are described in the annual report of the GRO(S).

The risks of developing cancer are likely to change over 10 years. One method of investigating these changes is to develop an age-period-cohort model which relates changes in incidence rates to these inter-related components of time, and then use the model to predict future changes in incidence rates. Risk factors for cancer are likely to be associated in different ways to these components of time. For example, the risk of developing most cancers increases with age. A typical example is lung cancer, for which the risk increases sharply from the age of about 45.

Secondly, the era, or period, that a person lives through may also influence his risk of getting cancer or his chance of being diagnosed and registered with cancer. Changes over time in diagnostic practice will create a period effect, an example being the introduction of the breast cancer screening programme, which is expected to increase cancer incidence in the screened age groups, with a subsequent decrease in older age groups.

Thirdly the 'cohort' effect relates to a person's date of birth. Cigarette smoking has produced a cohort effect on lung cancer age-specific incidence rates: they increased to their highest level in men born around 1900, and have declined for men born since then. For women the peak was reached for those born around 1920.

However, for the projections for the SNAP reports two estimates of cancer incidence in 2005 have been calculated. Method 1 simply takes account of changes between 1996 and 2005 in the size and age structure of the population. It assumes that age- and sex-specific incidence rates remain exactly the same in the year 2005 as they were in 1996. Taking lung cancer in men as an example, Method 1 gives a 15% increase in incidence between 1996 and 2005, due to the predicted increase over this time period in the proportion of men in the older age groups where the risk of contracting lung cancer is highest. Method 2, however, in addition to taking account of changes in the population, assumes that trends in age- and sex-specific incidence rates which have occurred over the period 1986-95 will continue into the future (with an adjustment for the expected impact of the screening programme on breast cancer rates). So, for example, lung cancer age-specific incidence rates declined in men over the period 1986-95. Method 2 makes the assumption that this trend will continue into the future, so that, even with the increased numbers of men in the older age groups, incidence of lung cancer in men is expected, using this method, to be 2% lower in 2005 than in 1996.

References

1. Black RJ, Sharp L, Kendrick SW. *Trends in Cancer Survival in Scotland 1968 - 1990*. Edinburgh, Information & Statistics Division, 1993.
2. Higginson J, Muir CS, Muñoz N. *Human cancer: epidemiology and environmental causes*. Cambridge: University Press, 1992.
3. Gillis CR, Hole DJ, Lamont DW, Graham AC, Ramage S. The incidence of lung cancer and breast cancer in women in Glasgow. *BMJ* 1992; **305:** 1331.
4. McPherson K, Steel CM, Dixon JM. Breast cancer - epidemiology, risk factors, and genetics. *BMJ* 1994; **309:** 1003-7.
5. Evans DGR, Fentiman IS, McPherson K, Asbury D, Ponder BAJ, Howell A. Familial breast cancer. *BMJ* 1994; **308:** 183-7.
6. Quinn M, Allen E on behalf of the United Kingdom Association of Cancer Registries. Changes in incidence of and mortality from breast cancer in England and Wales since introduction of screening. *BMJ* 1995; **311:** 1391-5.
7. Brewster D, Everington D, Harkness E, Gould A, Warner J, Dewar JA, Arrundale J. Incidence of and mortality from breast cancer since introduction of screening. [letter] *BMJ* 1996; **312:** 639-40.
8. Dos Santos Silva I, Swerdlow AJ. Sex differences in time trends of colorectal cancer in England and Wales: the possible effect of female hormonal factors. *Br J Cancer* 1996; **73:** 692-697.
9. International Agency for Research on Cancer. *IARC Monographs on the Evaluation of Carcinogenic Risks to Humans, Volume 61: Schistosomes, Liver Flukes and Helicobacter pylori*. Lyon, International Agency for Research on Cancer, 1994.
10. Scottish Forum for Public Health Medicine, Scottish Needs Assessment Programme (1996) Oral Cancer.
11. Scottish Cancer Intelligence Unit. Cancer Registration and Statistics Scotland 1986-1995. Information and Statistics Division, NHS in Scotland. Edinburgh, 1998.

3 PREVENTION AND EARLY DIAGNOSIS

A comprehensive cancer control programme must emphasise prevention and early diagnosis. It is thought that up to 80% of cancers are preventable by means already available.[1] Effective action to prevent cancer and encourage early diagnosis requires co-operation between health promotion departments, primary and secondary care and public health, working in partnership with relevant social, industrial, educational and political agencies.

Better application of what is already known should not be ignored in favour of apparently more attractive new technologies which have not been evaluated. In Scotland the Health Education Board for Scotland (HEBS) is responsible at a national level for health education. The wider aspects of health promotion are the responsibility of health boards. More effective prevention programmes are essential at local and national level.

3.1 PRIMARY PREVENTION

A wide range of factors contribute to the development of cancer. These include the environment, occupation, poor social circumstances, heredity and aspects of behaviour such as cigarette smoking, diet, alcohol consumption, sexual behaviour and sun exposure. Action is required at national, local and individual levels, using health promotion, education and policies. Because of the long latent period for most cancers between exposure to risk factors and development of disease, it is unrealistic to expect evaluation of specific health promotion activities to demonstrate reductions in incidence in the short term. It is also important to recognise that behavioural change in relation to lifestyle factors is a staged and gradual process.[2]

Smoking

Lung cancer, the most preventable of all cancers, remains the commonest cancer in every health board in Scotland. Evidence implicating cigarette smoking as the major risk factor was first published in 1952.[3] Health promotion activities to reduce smoking include non-smoking policies in workplaces, social settings and public places, targeted educational campaigns, the provision of accessible cessation services particularly to promote early cessation attempts by young smokers, and legislative programmes to increase the price of tobacco while reducing tobacco promotion and the availability of tobacco to young people.

There is evidence that advertising has a positive effect on cigarette consumption, and that advertising bans result in reduced consumption.[4] An economic study of a smoking cessation programme in Wales showed that the net value of benefits is considerably greater than costs for both the NHS and the economy, even if only 10% of the benefits could be attributed to the programme.[5] One study has estimated that up to 4000 new jobs could be created from the increased economic activity which would follow cessation of smoking in Glasgow.[6] Health professionals can be effective in promoting smoking cessation within the context of a comprehensive national anti-tobacco strategy.[7]

Lung cancer incidence in Scottish men peaked in 1979 and has been declining since, following a reduction in smoking prevalence. However in women, among whom the decline in prevalence started later, incidence continues to rise.[8] This rise started in the 1950s. By 1990 lung cancer overtook breast cancer as the commonest cancer among women in Glasgow.[9]

Overall smoking prevalence has been declining for the past twenty years or so, but this trend has levelled off in younger age groups.[10] A series of reports on health behaviours of schoolchildren showed that in comparison with nine other northern hemisphere countries Scottish children smoke less.[11] However the increasing prevalence of smoking in 15 year old girls is of concern. There are significant regional variations in Scotland, for example high rates of girls smoking in Grampian, Lothian and Dumfries and Galloway.[12] As uptake of smoking occurs almost exclusively among the under 18s, teenagers, particularly girls, remain a crucial market for the tobacco industry. The challenge to health promoters is to deliver effective programmes in this context.

Diet

The associations between diet and cancer are reviewed in the Scottish Office report *The Scottish Diet* [13] which includes recommendations for implementing dietary change, and possible means of surveillance and research. *Eating for Health* [14] is the action plan following the report. This sets out dietary targets for cancer prevention and specifies ways of promoting healthy eating, using a multi-agency approach. The National Dairy Council Factfile on Nutrition and Cancer [15] provides a useful summary of the evidence and concludes that “the strength of the evidence is still insufficient to permit anything but general statements when advising the public about diet and cancer.” An exception is made regarding the stronger association between alcohol and cancers of the mouth, pharynx, larynx, oesophagus and liver.

The Scottish diet, in common with the rest of the UK, is relatively high in fat and sugar. Of particular concern is the fact that average national consumption of fruit and vegetables is half the recommended amount of 400g daily. [13] In comparison with nine other northern hemisphere countries, Scottish 11 and 15 year olds have a relatively high consumption of fat and sugar, and low daily consumption of fruit, vegetables and fibre. Significant regional variations in diet are also reported, with particularly high rates of fat and sugar consumption in Strathclyde.[12]

Increasing uptake of fruit and vegetables in the diet should be a priority. This requires action on availability, accessibility and cost and has implications for the public and commercial sectors (schools, hospitals, retail) and the community.

Sun exposure

A major controllable risk factor for skin cancer is exposure to the sun.[16] A consensus statement on skin cancer prevention issued by a British working party recommends avoiding noonday sun, seeking natural shade, and using protective clothing, hats and sunscreen.[17] These guidelines should be included in primary prevention programmes, particularly for children and parents. A recent study of awareness of risk factors from Australia, which has the highest incidence of skin cancer in the world, showed that ignorance of risk and its avoidance remains despite a high level of publicity over the last 30 years.[18]

3.2 SECONDARY PREVENTION

The main strategies for secondary prevention of cancer are early diagnosis through the national screening programmes for cervical and breast cancer. Body self-awareness is important in promoting earlier presentation with symptoms suggestive of cancer. People need to know screening services exist, what they mean, and how to access them.

Cervical cancer

Cervical screening began in Britain in 1964, but it was only in 1987 that a government circular instructed health boards in Scotland to set up systematic programmes for screening the whole population. The decline in mortality from cervical cancer between 1973 and 1992 is shown in Figure 7 (Appendix 3). Aberdeen introduced systematic screening before elsewhere in Scotland and the fall in mortality from the disease there precedes the fall in the country as a whole. While this is not absolute evidence of the effectiveness of systematic screening, it is consistent with the pattern observed in Scandinavian countries with well organised screening programmes.[19]

Breast cancer

Breast screening was introduced on a national basis for women aged 50-64 years of age in 1988. The peak in incidence of node negative and small (less than 20 mm diameter) tumours in 1988-89 in west Glasgow, due to the first round of screening is shown in Figures 8 and 9 (Appendix 3). Process is being monitored nationally, and has been shown to meet quality standards.[20] Screening centre data will require to be linked to the cancer registry to monitor the contribution of the programme to reducing mortality.

Breast self-examination was initially considered to be of benefit in leading to earlier presentation,[21] but subsequently questions have been raised about the way in which this is taught to women and this approach has been replaced with promotion of “breast awareness”.[22] This encourages women to be aware of what is normal for them, informs them about what might be abnormal and explains what to do if there is concern. Voluntary organisations such as *Breast Cancer Care* play an important part in the dissemination of such information.

Melanoma

A public education campaign in the early 1990’s to encourage early detection of malignant melanoma resulted in earlier presentation and a reduction in mortality in women, but not in men.[23] This campaign involved education of health care professionals and the public using wide distribution of materials and the media.

Oral cancer

Although many oral cancers appear to arise *de novo,* several premalignant conditions are recognised. The detection and diagnosis of such lesions permits patients to be referred for advice regarding lifestyle and, where necessary, treatment. In the absence of evidence for the effectiveness of screening programmes in the general population, opportunistic screening of high risk groups by general medical and dental practitioners is recommended in a recent SNAP report.[24]

Other cancers

The evidence that population screening for other cancers e.g. prostate, colon and ovary is of benefit is still lacking.

Socio-economic Factors

Less affluent populations have poorer survival from a range of cancers,[25] and in the case of cervix and testis this has been shown to be due to later presentation.[26,27] Research is required on the mechanisms by which socio-economic deprivation influences survival.

The European Code Against Cancer

The evidence on the effectiveness of preventive strategies has recently been incorporated as the basis of preventive activity by the Europe Against Cancer Campaign. This has widely publicised a code comprising 10 guidelines on reducing risk. These are:

1. Do not smoke. Smokers, stop as quickly as possible and do not smoke in the presence of others. If you do not smoke, do not experiment with tobacco.
2. If you drink alcohol, whether beer, wine or spirits, moderate your consumption.
3. Increase your daily intake of vegetables and fresh fruits. Eat cereals with a high fibre content frequently.
4. Avoid becoming overweight, increase physical activity and limit intake of fatty foods.
5. Avoid excessive exposure to the sun and avoid sunburn especially in childhood.
6. Apply strictly any regulations aimed at preventing any exposure to known cancer causing substances. Follow Health and Safety instructions on substances which may cause cancer.
7. See a doctor if you notice a lump, a sore which does not heal (including the mouth), a mole which changes in shape, size or colour, or any abnormal bleeding.
8. See a doctor if you have persistent problems, such as persistent cough, persistent hoarseness, a change in bowel or urinary habits or an unexplained weight loss.
9. Have a cervical smear regularly. participate in organised screening programmes for cervical cancer.
10. Check your breasts regularly. Participate in organised mammography screening programmes if you are over 50 years.

EUROPE AGAINST CANCER CAMPAIGN
1995

3.3 ENVIRONMENTAL FACTORS

Environmental aspects of cancer cause great public concern because they are so often the focus of media attention. This is paradoxical when environmental factors are thought to account for only 5% of cancers. However, these concerns need to be addressed formally to allay public fear and anxiety.

Health services, local authorities and the newly formed Scottish Environment Protection Agency should act together to develop strategies to investigate and monitor relationships of air quality, radiation, water quality, soil contamination, waste disposal and occupation to cancer.

3.4 GENETIC TESTING

Migration studies show that genetically related cancer only accounts for up to 10% of the total, even where the evidence is strong, as in ovary and breast. However, two thirds of those presenting with genetically determined cancer are under fifty years of age.

Planners and providers of services need to understand the social as well as the clinical implications of developments in genetics for the population. Anxiety engendered in relatives of those who die from cancer, awareness of the possibility of testing for mutant genes which predispose to cancers of the large bowel, ovary and breast, and the interest of clinical geneticists, have fuelled the demand for familial cancer clinics which are currently provided by departments of clinical or medical genetics in Aberdeen, Dundee, Edinburgh and Glasgow.

A familial cancer clinic has four functions: obtaining an accurate and complete family history; advising about cancer risks and possible actions; arranging genetic testing where appropriate; and research and evaluation of cancer genetics.[28] The model preferred and practised in Scotland and in many other parts of the UK is a combined clinic in which geneticists, radiologists and breast surgeons co-operate.

The potential for primary prevention for people with a detectable genetic predisposition to melanoma, and cancers of the large bowel, breast and ovary is theoretical at present. Possible means are: risk factor avoidance, prophylactic drug treatment, and prophylactic surgery. The evidence for each of these has been reviewed.[29]

There is a strong case for prophylactic polypectomy or colectomy for those at high risk of colorectal cancer. However, while the risks of breast and ovarian cancer for those with the BRCA1 gene have been quantified, screening of those at high risk is required to identify those with disease, and evidence of the effectiveness of screening for ovarian cancer and of mammography in premenopausal women is still being sought.[30] Those for whom surgery is indicated should have access to specialist surgical services.

Research in cancer genetics is important because the hope for primary prevention of cancer lies in understanding the effect of mutation on gene function. This research, the collection of information on familial cancers, and the provision of a service to those whose families are affected are now part of a comprehensive programme of cancer control.

Cancer genetics poses dilemmas for the public and professionals. Health boards and providers including GPs need to be informed and have an opinion. Great care will be necessary in planning and putting in place services for cancer genetics given the ethical issues and incomplete evidence of effective strategies.

References

1. Austoker J (1994). Cancer prevention: setting the scene. BMJ 308:1415-20
2. Prochaska JO and Di Clemente CC (1986). Towards a comprehensive model of change. In *Treating Addictive behaviours: process of change*. Miller WR and Healther N (eds). Plenum, New York.
3. Doll R and Hill AB (1952). A study of the aetiology of carcinoma of the lung. BMJ (ii) 1271-86.
4. Smee C (1992). The effect of tobacco advertising on tobacco consumption. Health Trends 24 (4):111-112.
5. Phillips CJ, Prowle MJ (1993). Economics of a reduction in smoking: case study from Heartbeat Wales. Journal of Epidemiology and Community Health 47:215-223
6. Fraser of Allander Institute (1989). The regional economic impact of reduced cigarette expenditure by citizens of Glasgow. University of Strathclyde.
7. Health Education Authority (1993). Giving up smoking: does patient education work? HEA, London.
8. Black R, MacFarlane G, Maisonneuve P, Boyle P (1995). Cancer Incidence and Mortality in Scotland 1969-89. ISD, Edinburgh.
9. Gillis CR, Hole DJ, Lamont DW, Graham AC, Ramage S (1992). The incidences of lung cancer and breast cancer in women in Glasgow. BMJ 305:1331.
10. Gupta S (1996). Health Trends in *Health Trends.* Health Trends 28(1):3-4.
11. Currie C, Todd J, Thomson C (1994). Health Behaviours of Scottish Schoolchildren Report 4: The Cross-National Perspective. University of Edinburgh Research Unit in Health and Behavioural Change
12. Currie C and Todd J (1990) Health Behaviours of Scottish Schoolchildren Report 1: National and Regional Patterns. University of Edinburgh Research Unit in Health and Behavioural Change
13. Scottish Office Home and Health Department (1993). The Scottish Diet.
14. Eating for Health. A Diet Action Plan for Scotland. Scottish Office Department of Health, Edinburgh, July 1996
15. National Dairy Council (1995). Factfile number 12, Nutrition and Cancer. London.
16. Marks R and Whiteman D (1994). Sunburn and melanoma: how strong is the evidence? BMJ 308:75-76.
17. Marks R (1994). Primary prevention of skin cancer. BMJ 309:285-286.
18. Martin RH (1995). Relationship between risk factors, knowledge and preventive behaviour relevant to skin cancer in general practice patients in South Australia. British Journal of General Practice 45: 365-367.
19. Austoker J (1994). Screening for cervical cancer. BMJ 309:241-8
20. Scottish Breast Screening Programme Report 1993. ISD Publications, Edinburgh, 1993
21. Hill D, White V, Jolley D, Mapperson K (1988). Self examination of the breast: is it beneficial? BMJ 297: 271-275
22. Austoker J (1994). Screening and self-examination for breast cancer. BMJ 309:168-74.
23. Mackie R and Hole DJ (1992). Audit of public education campaign to encourage earlier detection of malignant melanoma. BMJ 304:1012-5.
24. Scottish Forum for Public Health Medicine, Scottish Needs Assessment Programme (1996) Oral Cancer
25. Carnon A et al, submitted for publication
26. Harding MJ, Paul J, Gillis CR, Kaye SB (1993). Management of malignant teratoma: does referral to a specialist unit matter? Lancet 341; 999-1002
27. Lamont DW, Symonds RP, Brodie MM, Nwabineli NJ, Gillis CR (1993). Age, socio-economic status and survival from cancer of cervix in the West of Scotland 1980-97
28. Ponder BAJ (1994). Setting up and running a familial cancer clinic. Brit Med Bull 50(3):732-745

29. Steel CM (1995). Implications of studies of inherited predisposition for prevention and treatment. In *The Genetics of Cancer.* Ponder BAJ and Waring MJ, Dordrecht
30. Campbell H, MacKay J, Porteous M (1995). The future of breast and ovarian cancer clinics. BMJ 311: 1584-5

4 CANCER TREATMENT: EVIDENCE FOR HEALTH GAIN

This chapter considers the evidence for specialisation in cancer treatment which forms the basis of the Calman-Hine and SCCAC Reports.[1,2] The research evidence on the effectiveness of cancer services is not completely conclusive in supporting a fully specialised service for all cancers. Most of the evidence comes from cancer registries and from special studies. The challenge has been to determine at what point in the production of such evidence action should be taken to change the service.

A range of cancers of varying incidence for which there is evidence about the benefits of specialist care has been selected by the Expert Advisory Group on Cancer of the Department of Health [3] and the evidence has been published.[4] The main points are:

Cancer in children

The evidence on the effectiveness of centralised specialist treatment is clear and well known.[4] Childhood cancer illustrates the principles central to the Calman-Hine Report and their application. The early clinical trials for treatment of childhood leukaemia involved guidelines rather than precise protocols. When paediatricians and others involved were learning about multi-modality therapy, there was little change until it was appreciated that controls in published clinical trials had a better survival outcome than children not in trials. Since then (early 70s), the gap between incidence and mortality has widened, reflecting improved survival.[5]

The success of the treatment of childhood leukaemia has been followed by success in the treatment of solid tumours in children. In view of the relative rarity of childhood cancer, doctors normally refer children suspected of childhood malignancy to a paediatric cancer centre and the majority of clinicians consider it unethical not to do so. The pattern illustrated by childhood leukaemia reflects these phases, and was associated with the closure of paediatric units in district general hospitals which previously treated it and other childhood cancers.

Rare cancers in adults

There is good evidence for survival advantage for patients treated with testicular cancers in specialist centres.[6]

Moderately common cancers in adults

The example of ovarian cancer shows that treatment by a gynaecologist followed by multi-disciplinary therapy improves outcomes and that these improvements exceed any benefit from a given specialist working alone. It appears to matter more what is done to patients and by whom than where it is done. A relationship between numbers of operations carried out and improved survival is still unproven.[4,7,8]

Haematological malignancies in adults

Studies from Finland have shown that the results of treatment of multiple myeloma resulted in significantly improved survival in those districts of Finland where patients were entered into prospective randomised trials and therefore treated according to protocol.[9] This had an overall impact on the results for the district and was not restricted to those entered into the trials.

Lung cancer

The impact of either radiotherapy or chemotherapy on long term survival is small and comparison between specialist and non-specialist care for these modalities has not been much studied. Patients in trials appear to survive slightly longer than others.[4]

Breast Cancer

Districts in Yorkshire where a high percentage of patients were treated by chemotherapy and hormonal therapy were associated with a significantly better survival. These two variables explain most of the variance in survival outcome between different treating surgeons regardless of whether these surgeons were in a teaching or non-teaching district. Case load appears to be important. The risk ratio of deaths is reduced by 15% for patients managed by surgeons with an annual case load of more than 30 patients.[10,11] As previously shown in ovarian cancer, the number of operations performed is not necessarily a major factor whilst skill of the surgeon appears to be. The components of skill have yet to be determined. A recent study from the West of Scotland showed that care by units with a specialist interest in breast cancer showed a 10% survival advantage at 5 years and 8% survival at 10 years which rose to 17% when age, social class and nodal status were taken into account.[12]

The Cancer Guidance sub-group of the Clinical Outcomes Group has recently published guidance for planners on *Improving Outcomes in Breast Cancer* (1996).[13] This is based on a systematic literature review and recommendations on good practice are graded according to the quality of the evidence.

Colon and rectum

Survival outcomes in patients undergoing curative resection are much better, and fewer complications occur, in patients treated by surgeons with a high level of surgical skill.[14]

Meta analyses

Since publication of the above, meta analyses of the effect of specialisation on breast, ovarian, haematological and a variety of other cancers have been carried out by the Italian Cochrane Centre in Milan. These are shown in Figures 10-14 (Appendix 4).

Summary

The evidence for better long term outcomes with specialised care is strongest for breast, ovarian and haematological cancers and the rare cancers of childhood and adults (including testicular). For gastrointestinal and lung cancer most evidence suggests benefits in immediate surgical outcomes from specialised practice. Evidence points to benefits from specialised care in long term survival in colorectal cancer.[4]

References

1. Expert Advisory Group on Cancer (1995). A Policy Framework for Commissioning Cancer Services. Department of Health and Welsh Office.
2. Scottish Cancer Co-ordinating and Advisory Committee (1996). Report of Commissioning Cancer Services Sub-Committee. Scottish Office Department of Health.
3. Selby P (1994). A Policy Framework for Commissioning Cancer Services-Review of Evidence Supporting Specialised Cancer Care and the Recommended Network of Cancer Services.
4. Selby P, Gillis CR, Haward RA (1996). Benefits from specialised cancer care. Lancet 348:313-318.
5. Gillis CR (1988). The Epidemiology of Human Cancers. Chapter 1 in Oncology for Nurses and Health Care Professionals volume 1. Harper & Row, London.
6. Harding MJ, Paul J, Gillis CR, Kaye SB (1993). Management of malignant teratoma: does referral to a specialist unit matter? Lancet 341; 999-1002
7. Junor EJ, Hole DJ, Gillis CR (1994). Management of ovarian cancer: referral to a multi-disciplinary team matters. Brit J Cancer 70:363-370
8. Gillis CR, Hole DJ, Still RM, Davis J, Kaye SB (1991). Medical audit, cancer registration and survival in ovarian cancer. Lancet 337:611-2
9. Karjalainen S, Palva I (1989). Do treatment protocols improve end results? A study of survival of patients with multiple myeloma in Finland. BMJ 299: 1069-72
10. Sainsbury R, Rider L, Smith A, MacAdam A on behalf of the Yorkshire Breast cancer Group (1995). Does it matter where you live? Treatment variation for breast cancer in Yorkshire. Br J Cancer 71(6):1275-78
11. Sainsbury R, Haward RA, Rider L, Johnson C, Round C (1995). Influence of clinician workload and patterns of treatment on survival from breast cancer. Lancet 345:1265-70
12. Gillis CR, Hole DJ (1996). Survival outcome of care by specialist surgeons in breast cancer: a Study of 3786 patients in the West of Scotland. BMJ 312:145-8
13. Clinical Outcomes Group, Cancer Guidance sub-group (1996). Improving outcomes in breast cancer. NHS Executive, Department of Health.
14. McArdle CS, Hole DJ (1991). Impact of variability among surgeons on postoperative morbidity and mortality on ultimate survival. BMJ 302:1501-5

5 CANCER CARE: SERVICE SPECIFICATION

5.1 The development of clear written specifications for cancer services is an important element of planning and improving cancer care. Chapter 2 has indicated the burden of cancer which needs appropriate health interventions. Chapters 3 and 4 summarise the evidence base for treatment. Experts concur that optimal cancer care should be delivered by an integrated service spanning primary, secondary (cancer unit) and tertiary (cancer centre) care. Planners should specify a coherent programme of cancer care across these settings. Multidisciplinary team management is the favoured model. This chapter describes the contribution of Primary Care. Palliative care is discussed in that setting. Secondary and tertiary level (cancer unit and cancer centre) specialist services are then described. Specification of appropriate clinical audit is a vital element of high quality care and is discussed in the next chapter on quality assurance.

5.2 A number of different elements go to make up the care for each group or type of cancer. These include appropriate referral, timeous outpatient consultation, investigation as either outpatient, day or inpatient; and treatment either as outpatient, day case or inpatient. Primary care, cancer units and cancer centres all contribute to these care pathways. The services to be provided by each provider, and the standards to which the service should be delivered, must be specified. Multidisciplinary cancer care should be effectively co-ordinated, involve regular case management discussions, and encompass all aspects of care including counselling and palliation. This will require commitment of time by lead and specialist clinicians.

5.3 Since both haematology and non-surgical oncology require similar support in terms of nursing, pathology, and pharmacy ways of developing joint services should be considered, where appropriate transcending existing management boundaries or historical patterns of practice.

PRIMARY CARE

5.4 PRIMARY CARE

The central role of primary care in the provision of cancer services has been emphasised in the SCCAC Report [1]. Detailed consideration of both primary and palliative care has been set out in a further report.

Caring for cancer patients ideally involves a therapeutic relationship where there is awareness that life may be shortened and distressing symptoms may occur. The GP and other members of the primary care team should provide continuity of care and an holistic approach to the patient. This involves co-ordinating care directed towards treatment of the disease, relief of symptoms, social support and maximising quality of life.

Specifications under the following headings are required.

5.4.1 Prevention and early diagnosis

The organisation of Health promotion in general practice in Scotland was changed in October 1996 from ‘banding’ system to a professionally led, practice-based one (Scottish Office Department of Health Circular PCA(M)(1996)20). There is now evidence that opportunistic advice from GPs is the key intervention in smoking prevention, and that this is enhanced by follow-up support. [2] A review of the literature on effectiveness and cost-effectiveness of health promotion in primary care is included in the SNAP report *Health Promotion in Primary Care* [3] aimed at helping planners and providers of services to formulate a strategy for health promotion in primary care.

Early referral

Delay in diagnosis may be due to fear, lack of awareness of or understanding of the significance of symptoms by patients, or to delays in appropriate access to hospital services. Since the GP is usually the first point of contact patients have with health services, it is important that referral pathways are worked out jointly between GPs and specialist clinicians. GPs need to determine and follow best practice in referral. Definition of cancer units and centres as recommended by the SCCAC Report should optimise referral routes and access for patients.

Screening

Primary care has a central role in the uptake of cervical and breast screening. Both of these programmes involve a multi-stage process requiring close collaboration with primary care. Screening for oral cancer is carried out by dentists as part of routine check-ups. GPs should also be encouraged to examine opportunistically the mouths of those with increased risk of oral cancer i.e. smokers, heavy drinkers, the elderly and those from lower socio-economic groups.

The primary care team can contribute to the prevention and early diagnosis of skin cancer by means of skin screening clinics, advice on skin protection, and identification of high risk individuals.[4,5,6]

5.4.2 Treatment

The GP has an important role in discussing treatment options with patients, particularly where prognosis is poor, in delivering care between hospital attendances, and in dealing with the effects on family and carers. This requires adequate postgraduate support.

5.4.3 Palliative care

All patients with cancer and their families require care with a palliative approach throughout the course of the illness. 40% all cancers in Scotland are rapidly fatal and virtually all cancer patients will consult their GP in the last year of life.[7] The strengths of palliative care provision in primary care, and areas for improvement, are detailed in a recent report of the Scottish Partnership Agency for Palliative and Cancer Care [8] and in the second report of the SCCAC Commissioning Cancer Services Subcommittee.[1] Recommendations are made to facilitate integration of specialist palliative care with primary care, cancer units and cancer centres, and examples of good practice are given. A form of shared care similar to diabetic or antenatal care is likely to be optimal for cancer patients.

Seamark et al showed that the proportion of patients dying in an appropriate community setting could be improved.[9] In a study on the care of the dying and bereaved in Argyll and Clyde, death occurred at home in only 30% of cases where bereaved relatives or friends reported a preference for this.[10] The main reasons given by GPs for this were lack of carer or carer support, non-availability of 24-hour nursing or need for complicated nursing procedures, and need for specialist symptom control. These findings relate to deaths from a variety of causes, but illustrate the team approach required to care for cancer patients in the community. There is evidence of need for increased carer support to enable patients to be cared for at home. [11] This is an example of the kind of need which could make a major difference to quality of life in cancer patients but is often not identified by current planning and management processes.

Those responsible for allocating resources should take into account the need to integrate palliative care across secondary and primary care to enable adequate professional staffing and training, and appropriate carer support and respite and encourage development of more community-based palliative care.

5.4.4 Communication

The process of communication between hospital and general practice often appears poor. This is a key theme in the second report of the SCCAC Commissioning Cancer Services Subcommittee.[1] Service specifications should require at a minimum a discharge summary conforming to the standards of the SIGN document,[12] sent by first class post or electronic mail on the day of discharge. This should contain patient identification, diagnosis, procedures undergone in hospital, discharge prescription and follow-up arrangements. It is particularly important that GPs are informed about the patient's awareness of their diagnosis and prognosis.

Information needs also to be communicated to the GP from subsequent outpatient consultations for any purpose, but especially those involving discussion about treatment options and any change in treatment regime.

5.5 PALLIATIVE CARE

5.5.1 The levels of palliative care need to be clearly defined. These are:

Generalist palliative care
Care with a palliative approach is the standard of care expected of the GP, hospital doctor, community and hospital nurse. It addresses the physical, psychosocial and spiritual needs of the patient and carer.

Specialist palliative care
The level of palliative care provided by a health professional who has undergone a recognised and College approved training programme. Currently this is four years for doctors pursuing a career in palliative medicine with a preceding sound medical training.

Specialist palliative intervention
Practised by clinical and medical oncologists, and designed to reduce the cancer burden. This group of physicians will also practice generalist palliative care.

Palliative care can be considered as the fourth modality of cancer care. The reasons are:

- **Late presentation**: Many patients present when palliation is the only appropriate therapy.

- **Poor symptom control**: There has been little published evidence on the standard of palliative care in Scotland. One study of the care of the dying found poor attention to basic needs such as quenching of thirst and contact with nursing staff as death approached.[13] There is evidence from elsewhere of poor support for patients and their carers,[14] and of insufficient community support for patients wishing to die at home.[15]

- **Specialist palliative care is effective**: It has been shown that application of simple guidelines such as those produced by WHO in 1986 can lead to good pain and symptom control in the majority of cases.[16] These guidelines can be followed successfully by generalists. From the evidence available, it is reasonable to expect that the majority of palliative care can be delivered by the primary care team, but not without training and the support of the specialist palliative care team. For those patients with more complicated, severe or multiple problems, specialist palliative care has been shown to be effective in improving the control of pain, nausea, insomnia, anorexia and constipation.[17]

5.5.2 Integration of palliative care with other services

An important principle of palliative care is that it should be available at all stages of a patient's illness. To this end, palliative care should be integrated with cancer services in the community, in cancer units and in cancer centres. The Scottish Partnership Agency for Palliative and Cancer Care (SPAPCC) is currently developing models of good practice to facilitate this.

Each cancer unit, cancer centre and primary care team should have access to a specialist palliative care team, which might be located either in a hospital or hospice depending on local circumstances. Such a team would provide specialist palliative care within the cancer unit and train general staff in basic palliative care. It would also be responsible for integrating with and contributing to palliative care in the community. Some hospices have a home care team which performs this function. The appointment of primary care palliative care facilitator is another way in which this can be achieved.

Written specifications for cancer services which set standards for palliative care provision would enhance the quality of palliative care, for example that there should be a nurse with palliative care training on duty in every ward caring for cancer patients.

The inclusion of both primary and palliative care representatives on Regional Cancer Services Groups would facilitate the improvement in communication required.

SECONDARY AND TERTIARY LEVEL (CANCER UNIT AND CANCER CENTRE) CARE

5.6 SURGICAL ONCOLOGY

At present the changes in service provision implied by the SCCAC Report may affect surgery more than the other modalities of cancer care. Interim designation of specialist surgeons will largely determine which hospitals or combinations of hospitals may be designated as cancer units for treatment of some cancer types.

5.6.1 Designation of specialists and cancer units

Functional arrangements are required to enable the provision of specialist surgical services for the commoner tumours. In many district general hospitals year-round service may require support from another cancer unit or the cancer centre.

For example, a minimum of two surgeons with specialist training is required to allow for training, holiday cover and support for other clinicians. The nature of specialisation is complex and remains to be defined. Ultimately, the results of prospective audit will confirm the designation of specialist surgeons. Many surgeons recognise that the volume of surgical operations carried out is not necessarily related to the quality of the surgery or the outcome. Surgeons with the requisite skills and interest to manage patients with particular tumours need to identified, and this should form the basis of cancer unit designation. The support of appropriate non-surgical oncology, specialist palliative care, nursing, and pharmacy services is essential to the provision of a specialist surgical service.

5.6.2 General surgeons in district general hospitals

Increasingly district general hospital surgeons have a special interest which will have to be further defined in the context of the cancer centre/ cancer unit structure. The available evidence points towards there being a volume of caseload which is associated with better outcomes.

5.7 NON-SURGICAL ONCOLOGY

Since most non-surgical oncologists are based in cancer centres, the issues arising from the SCCAC Report for this specialty differ from those for surgical oncology.

The challenge is to make optimal use of staff resources which are currently overstretched by the need to provide a service in the centre and in surrounding hospitals, and increasingly in non-hospital settings. Such arrangements have in many cases arisen in an unplanned fashion.

Specialisation may be as necessary in non-surgical oncology as it is in surgical to deliver specialist services for cancer in a consistent manner.

5.7.1 Designation of cancer units

Once cancer units are identified, non-surgical oncology outreach services should be concentrated in these. The advantages of facilitating the administration of chemotherapy in cancer units would be treatment of patients as close to their homes as possible. The benefit to cancer unit clinicians would be increased local contact with non-surgical oncologists

5.7.2 Planning

Planning for non-surgical oncology is required to optimise use of the non-surgical oncology resources of the cancer centre. This would rationalise non-surgical oncology support to surrounding units and define appropriate nursing and pharmacy resources required in these.

5.7.3 Chemotherapy in cancer units

The bulk of chemotherapy for common tumours can be given in the cancer unit, provided there is sufficient oncology nursing, haematology and pharmacy support. Such support could be shared between trusts working together as functional cancer units. Outreach oncology services can be developed further, including treatment at home for selected patients.

Since haematology and non-surgical oncology require similar nursing, pathology and pharmacy support, ways of sharing these resources should be sought.

5.7.4 Equipment

Regular replacement of linear accelerators on a national basis is needed in order to prevent equipment breakdowns which delays and reduces the number and effectiveness of radiotherapy treatments. Interruptions in radiotherapy have been shown to result in poorer survival outcomes for certain tumours.[18] Over time resources become seriously stretched as the intensity of treatment and its complexity rise. This needs to be planned and managed prospectively and on a regional level given the cost and complexity of this treatment..

A long term replacement programme is essential. Clinicians require the support of planners to ensure adequate staffing, equipment and facilities for patient care, teaching, research and audit.

5.7.5 Arrangements and environment of patient care

The amenity of patients' surroundings in cancer centres, and communication with clinicians, especially for those who live far away, deserves continuous attention as it has a major effect on the quality of life of patients.

5.8 HAEMATOLOGY

Guidelines on the provision of facilities for adult patients with haematological malignancies have been published by the Clinical Haematology Task Force of the British Committee for Standards in Haematology.[19] These describe four levels of care and the facilities required to treat particular groups of patients:

1. General haematology patients
2. Remission induction patients
3. Autologous transplants
4. Related allogeneic bone marrow transplants

In Scotland, all hospitals with a haematologist can deliver level 1 care, and many can deliver level 2 care. Levels 3 and 4 require specialist provision. Details of the capital requirements, staffing, blood transfusion and laboratory support are given in the guidelines.

Blood and bone marrow transplantation requires a centralised service. It may be possible to arrange for patients requiring autologous transplants to have initial treatment in a central unit, but aftercare in a DGH. Such arrangements require to be worked out on a regional basis. This is already happening in the West of Scotland: a Working Group of the West of Scotland Health Boards Purchasing Network has produced a report on blood and marrow transplantation which makes recommendations on future service provision.

5.9 GYNAECOLOGY

5.9.1 Specialist Centres

The Royal College of Obstetricians and Gynaecologists (RCOG) and the British Gynaecology Cancer Society have issued guidance on specialist treatment of gynaecological cancers.[20] This discusses caseload and defines the facilities and staffing of the Gynaecological Oncology Centre.

5.9.2 Subspecialisation

Gynaecological oncology is one of the four subspecialties for which the RCOG has had a training programme over the past ten years. Consultants trained before that may have a declared special interest.

5.9.4 Non-surgical oncology

Increasingly there is a need for specialised non-surgical input, especially in units where there is no gynaecologist with sub-specialty or special interest training.

5.10 SPECIALIST CANCER NURSING

The evidence base for planning nursing services for people with cancer is insufficient. As yet there is no **definitive** information on the staffing needs in cancer units or centres, on the appropriate grading and skill mix of nursing staff in the hospital and community, or on the identification of anatomical sites where nursing care requires highly specialised knowledge and skills and, most importantly, on the extent to which these may improve outcomes.

The Royal College of Nursing issued *Guidelines for Commissioners of Cancer Nursing Services in Scotland* in 1996*.* These recommend standards for nursing in district general hospitals, cancer centres, hospices, and the community. Levels of knowledge, skills and education required to care appropriately for cancer patients are outlined. Comment is made on areas where cost-effectiveness and quality of care have been demonstrated, for example breast cancer care, stoma care, pain control, palliative care and chemotherapy administration.

A guidance note on cancer nursing services describing the nursing skills required for the care and treatment of cancer patients in hospital and the community was published with MEL(1997)66. [21]

5.11 PATIENT SUPPORT

Voluntary organisations - Cancer Relief Macmillan Fund, Marie Curie Cancer Care, BACUP, TakTent, indeed the hospice movement as a whole - play an important part in cancer services for patients and their families.

The major cancer charities provide funding for staff, facilities and research which complements the provision by the NHS and other statutory sources. However, as this contribution is not always integrated fully into the care arrangements for individual patients the effectiveness of the contribution may not be optimal. Planners and providers of cancer care in primary care, cancer units and centres should be more aware of this valuable contribution.

Many individuals wish to volunteer time and energy to various cancer support groups. This voluntary effort, if properly directed, can complement the care provided by professionals.

5.12 OTHER PROFESSIONAL AND TECHNICAL SUPPORT FOR CANCER SERVICES

Effective cancer services and the optimal contribution of clinicians to them are critically dependent on a range of other professional and technical support. It is not possible to explore this in depth but helpful to refer to three examples.

1 Pathology

The diagnosis and treatment of cancer requires access to specialist pathology services which can offer accurate staging and a full range of cyto- and histopathological techniques. All laboratories should be CPA accredited and have internal quality control and external quality assurance arrangements in place. Some initial guidance has been issued by SCACC.

2 Pharmacy

Pharmacists in the community and in hospital make an important contribution to cancer care, particularly in pain control and complex chemotherapy. The second SCACC report on Commissioning Cancer Services contains details of the particular role of pharmaceutical services in managing patients with cancer in the community.

3 Imaging services

Requirements for imaging services support for cancer centres and cancer units were summarised in additional guidance issued by the Scottish Office Department of Health on 18 November 1996.

References

1. Scottish Coordinating and Advisory Committee (1996). Report of Commissioning Cancer Services Subcommittee on Primary and Palliative Care issued for consultation by Scottish Office Department of Health.
2. Barth A (1994). Smoking: A Review of Effective Interventions. Anglia and Oxford Regional Health Authority, Cambridge.
3. Scottish Needs Assessment Programme (1996). Health Promotion in Primary Care. Glasgow, Scottish Forum for Public Health Medicine.
4. Jackson A (1995). Prevention, early detection and team management of skin cancer in primary care: contribution to *The Health of the Nation* targets. British Journal of General Practice 45:97-101.
5. Johnson N, Mant D, Newton J, Yudkin PL (1994). Role of primary care in the prevention of malignant melanoma. British Journal of General Practice 44:523-526.
6. Mackie R and Hole DJ (1992). Audit of public education campaign to encourage earlier detection of malignant melanoma. BMJ 304:1012-5.
7. Higginson I (1996). Palliative and Terminal Care. DHA Project: Epidemiologically based Needs Assessment Series 2.
8. Scottish Partnership Agency for Palliative and Cancer Care (1996). The Integration of Palliative Care with Cancer Services. SPAPCC, Edinburgh.
9. Seamark DA, Thorne CP, Lawrence C, Gray DJP (1995). Appropriate place of death for cancer patients: views of general practitioners and hospital doctors. British Journal of General Practice 45:359-363.
10. Scott SN (1995). Task Force on the Care of the Dying and Bereaved in Argyll and Clyde Health Board.
11. Jones RVH, Hansford J, Fiske J (1993). Death from cancer at home: the carers' perspective. BMJ 306: 249-51
12. Scottish Intercollegiate Guidelines Network (1996). Interface between the hospital and the community: The immediate discharge document. Royal College of Physicians, Edinburgh.
13. Mills M, Davies HTO, Macrae WA (1994). Care of dying patients in hospital. BMJ 309:583-6
14. Sykes NP, Pearson SE, Chell S (1992). Quality of care of the terminally ill: the carer's perspective. Palliative Medicine 6:227-236
15. Addington-Hall JM, MacDonald LD, Anderson HR, Freeling P (1991). Dying from cancer: the views of bereaved family and friends about the experiences of terminally ill patients. Palliative Medicine 5:207-214
16. Zech DFJ, Grond S, Lynch J, Hertel D, Lehmann KA (1995). Validation of World Health Organisation Guidelines for cancer pain relief: a 10-year prospective study. Pain 63:65-76
17. Ellershaw JE, Peat SJ, Boys LC (1995). Assessing the effectiveness of a hospital palliative care team. Palliative Medicine 9:145-152
18. Hendry JH et al. A modelled comparison of the effects of using different ways to compensate for missed treatment days in radiotherapy. Clinical Oncology 1996; 8: 297-307.
19. British Committee for Standards in Haematology Clinical Haematology Task Force (1995). Guidelines on the provision of facilities for the care of adult patients with haematological malignancies (including leukaemia and lymphoma and severe bone marrow failure). Clin Lab Haem 17:3-10
20. Royal College of Obstetricians and Gynaecologists and The British Gynaecological Cancer Society (1996). Response to "A Policy Framework for Commissioning Cancer Services".
21. Commissioning Cancer Services in Scotland: Guidance on Pharmaceutical Services and Nursing Services. NHS MEL(1997)66.

6 CANCER CARE: QUALITY ASSURANCE

6.1 The quality assurance in clinical care involves demonstrating evidence-based practice. Investment in this process represents value for money. This necessitates a critical path from appropriate fundamental research, both epidemiological and experimental, through development to continuing professional development, service models and guidelines to protocols which are audited to demonstrate standards are being met.

6.2 The SCCAC Report outlines a model of service. Its outcomes need to be assessed through prospective audit.

Monitoring is required to determine :

- that what is planned is provided, and
- how much the new framework of services improves outcomes in cancer care

6.3 Research and Development

6.3.1 The evidence used by the Expert Advisory Group on Cancer showing the benefit to patients of a specialist and multi-disciplinary approach to the treatment of cancer has been published [1] (see chapter 4) but insufficient research is taking place to fill the gaps.

6.3.2 It is important for planners to identify these gaps to assist the case for research funding from the Chief Scientist and the NHS Research and Development Programme.

6.3.3 A recent editorial comment in the British Medical Journal, referring to publication of the evidence on specialisation and improvements in breast cancer outcome, says that such research "illustrates how dramatic improvements may come from research in the organisation and delivery of care, and perhaps we can expect as much from such unglamorous health services research as we can from molecular biology".[2]

6.3.4 Evidence based policy and commissioning is necessary in relation to new developments in cancer treatment. Cancer centres should give advance warning to planners on clinical trials their residents are to be involved with, the scientific status of these, and the costs of continued treatment once the trial has finished. It is also essential to ensure that all elements of funding required to support clinical research and trials are identified and fully provided for from the appropriate source. Failure to do so will deny resources to other patients.

6.3.5 Increased collaboration between teaching hospitals and district hospitals in recruiting patients for clinical trials is required. There is evidence that the conduct of clinical trials may influence consistency of treatment in an area and improve outcomes. [3]

6.3.6 A robust information base on cancer risk factors such as smoking prevalence is needed as a baseline for health promotion activities. Needs assessment in primary care is necessary to enable the primary care based planning envisaged by the Shields report.[4]

Economic evaluation

6.3.7 The cost of cancer services in the UK exceeds £1500m[1]. Considerable effort is required to ensure maximum cost effectiveness of this expenditure. Economic evaluation is needed at two levels, one the level of service models and the other the process of care for individual cancers.

Service Models

6.3.8 The SCCAC Report acknowledges that implementation of the action plan for planning cancer services will have financial implications. Such costs should be considered in the context of all potential costs and benefits. Selby and Haward (personal communication) consider that initiation of the planning framework could be carried out at modest cost.

6.3.9 Estimation of additional local costs requires detailed knowledge and involvement in:

- the existing state of cancer services and local specialist facilities
- the definition of a cancer unit
- the impact on provider units of workload changes as a result of implementation

Option appraisal

6.3.10 An appropriate economic approach to implementing the new model of cancer services would be option appraisal. This involves identifying all the possible service configurations that would fulfil the SCCAC recommendations and comparing them in terms of the costs involved and their performance against a series of benefit criteria. These include:

- accessibility of services for the local population
- speed of implementation
- threat to provider viability
- fit with plans of neighbouring planners
- GP opinion
- future planning flexibility

6.3.11 Options could be scored against criteria using objective evidence wherever possible, such as in the case of accessibility to the resident population, but quantifying subjective judgements in other areas. An added refinement would be to weight the different criteria to reflect their relative importance, allowing a weighted total score to be calculated and compared to costs. A decision could then be reached on the basis of the information in the matrix.

Advantages of option appraisal

6.3.12 This approach has potential advantages:

- it gives the opportunity for a range of ways of implementing the recommendations to be proposed and discussed
- it focuses attention on the most important factors that will affect a decision
- the process of scoring the performance of options allows the issues to be thoroughly debated and differences in opinion and judgement brought out
- it provides a transparent basis for decision-making for further discussion with all interested parties.

This type of planning approach is potentially constrained by difficulties in costing services, lack of agreement on priorities and local specialty and political intents. It requires strong leadership and commitment to carry through.

6.4 Guidelines and Protocols

6.4.1 The use of evidence-based clinical guidelines is a powerful means of improving cancer outcomes. Local protocols for implementation of national guidelines are needed. Clinicians should take the lead in this as ownership is an important prerequisite for implementation.

6.4.2 National guidelines available at present include those on the management of ovarian cancer, prepared by the Clinical Resource and Audit Group (CRAG) and published in 1995. Nationally produced evidence based clinical guidelines are available from the Scottish Intercollegiate Guidelines Network (SIGN) on Palliative Radiotherapy for Non Small Cell Lung Cancer, and on the management of lung, breast, colorectal and testicular cancers.

6.4.3 There can be however general agreement among clinicians on what constitutes "best practice" in clinical management of a number of cancers, for example, endometrial, cervical, vulval and other rarer gynaecological cancers. National guidelines and local protocols making this explicit are required.

6.4.4 Palliative care guidelines have been developed jointly by the Scottish Partnership Agency for Palliative and Cancer Care (SPAPCC) and CRAG.[5]

6.4.5 A Guide to Drug Prescribing in Palliative Care has been prepared as part of a CRAG funded audit of pharmaceutical care provided to terminally ill patients in the hospice and community.[6]

6.5 Clinical Audit

6.5.1 Clinicians accept that development and implementation of evidence-based care protocols is a key to treatment outcome, but this needs to be established and evaluated on a population basis by means of prospective audit. The key to success in this is to bring together all those involved in treatment. Professionally led prospective audit is essential for monitoring the quality of care including survival outcomes. This information has not been available to date from routinely collected data. Because of the need to correct for age, stage at diagnosis, socio-economic status, co-existing disease, and cause of death this information can only be obtained at the moment by epidemiological studies involving perusal of case notes. A national system of audit using agreed routine core datasets, adapted for local use, is likely to be the most cost-effective situation and should be an integral part of the cancer service in Scotland. This would allow audits of different anatomical sites to be conducted over appropriate time periods for statistical validity.

6.5.2 Palliative care should also be audited prospectively in hospices, cancer centres, cancer units, and in the community. The views of patients, relatives and carers should be sought. It is difficult to measure the quality of palliative care, but outcome measures and tools for auditing these are being developed.[7]

Audit in primary care

6.5.3 This is now an essential activity for training practices and trainees in general practice. Because of the time and resources involved, ways need to be found of facilitating its extension to all practices. CRAG commended a scheme in one health board, which employed multi-professional general practice audit assistants, as a model.[8] Elements of cancer care could be incorporated into such a scheme.

6.5.4 Regular feedback to practices from health boards on cancer incidence and outcomes, either on individual practice or locality basis, would inform GPs and direct their efforts to improve cancer care.

What can be monitored?

6.5.5 Structure, process and outcome can be monitored. Audit of structure will increasingly compare the availability of specialist skills, their deployment in clinical networks and interaction with the cancer centres and the provision of technical support and information structure against explicit standards and criteria.

6.5.6 Survival outcome and its quality must now be measured, together with patient satisfaction. The latter has considerable methodological difficulties which are the subject of current quantitative and qualitative research. For patients not receiving treatment designed to prolong survival, appropriate measures would be, for example, concordance of place of death with the patients' and relatives' wishes, and symptom control. Some health boards are carrying out studies of patient satisfaction with the service. There is considerable scope for this work to be extended and shared across Boards. A study funded by the Cancer Research Campaign shows clearly that patients' information needs are considerable.[9] This was also highlighted in the second SCACC report on Commissioning Cancer Services.

6.5.7 Another important aspect of audit is to find out what takes place in the informal network of carers of those with cancer. This is taking place in a number of locations in Scotland and there is considerable enthusiasm on behalf of both doctors and nurses to find out more about this important and under-researched area.

6.5.8 It should be remembered that it will take five years for improvements in survival outcome to be demonstrated at locally perceptible levels.

Data sources

6.5.9 These include the population-based cancer registry, Registrar General Office mortality data, pathology laboratories, case records and the national Scottish Morbidity Recording schemes including COPPISH. The population base for outcome measurement is either local, regional or national, depending on the subject of the denominator and the numbers affected by each tumour.

6.5.10 The cancer registry is the obvious denominator because it is national, inviting these local comparisons which are statistically appropriate. It is clinically neutral and reasonably up-to-date. At present this is confined to identifying information; details on which the diagnosis rests; the date treatment commenced and whether the patient is known to be dead. Following a review of the scheme and future requirements of users an implementation group has been set up to extend its content throughout Scotland to include information on pathological stage for breast and colorectal cancer. It is also hoped to link this information with information on breast and cervical screening. Clinical acceptability may require more detail than can be provided at present on other than a research basis. In this context the growing potential of record linkage techniques has much to offer.

The example of ovarian cancer

6.5.11 This is a useful example because the major prognostic factors are known: age, stage, socio-economic group, tumour type, histological grade and ascites. The process variables could be:

- clinician who first operated on the patient,
- outcome of the operation,
- chemotherapy delivered, and
- attendance at multi-disciplinary clinic.

6.5.12 The study on ovarian cancer by Junor et al is one of the first to show the independent survival benefit of multi-disciplinary therapy.[10] Recent unpublished evidence points to an increase in the use of multi-disciplinary therapy, but not in referrals to a specialist gynaecologist. The reason why the audit of ovarian cancer has to be conducted on the basis of these variables is because clinicians accept them, and it is this evidence that forms the basis of the Scottish Guideline.

6.6 Continuing Professional Development

6.6.1 Cancer control constitutes a wide range of interventions, primary prevention, health education, early diagnosis and screening, treatment, rehabilitation, palliative care, information, evaluation, research, organisation and management. Education on these topics should start at undergraduate level. There is a need now for a programme of education for appropriate health professionals currently in post, including those in primary care. Competing demands from other national programmes require to be prioritised.

6.6.2 Plans for programmes of postgraduate education and specialist training need to take account of existing and projected shortages of key disciplines. Shortages are being exacerbated by the increased demand for specialist cancer services. For example, shortages in non-surgical oncology have been exacerbated by increased recruitment in England and Wales following publication of the Calman-Hine Report. At present there are insufficient trainees to fill the available consultant posts in palliative care in Scotland. Poor job satisfaction due to inadequate resources is adding to the difficulties in recruiting consultants.

References

1. Expert Advisory Group on Cancer (1995). A Policy Framework for Commissioning Cancer Services. Department of Health and Welsh Office.
2. Editorial comment BMJ 1996;312
3. Selby P, Gillis CR, Haward RA (1996). Benefits from specialised cancer care. Lancet 348:313-318.
4. Commissioning Better Health (1996). Report of the Short Life Working Group on the Roles and Responsibilities of Health Boards.
5. Scottish Partnership Agency for Palliative and Cancer Care/ CRAG (1994). Palliative Cancer Care Guidelines. Scottish Office Home and Health Department
6. Leishman JG (1994). A Guide to Drug Prescribing in Palliative Care. Scottish CAPO Publications
7. Higginson I (1995). Outcome Measures in Palliative Care. National Council for Hospice and Specialist Palliative Care Services.
8. Trust P, Brown C, Johnstone C (1995). General Practice Audit Assistant Scheme in Argyll and Clyde. Clinical and Audit Resource Group Occasional Paper no 68, National Health Service in Scotland, Edinburgh.
9. Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, Fallowfield L. (1996) Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. BMJ 313: 724-6.
10. Junor EJ, Hole DJ, Gillis CR (1994). Management of ovarian cancer: referral to a multi-disciplinary team matters. Brit J Cancer 70:363-370

APPENDIX 5

COMMISSIONING CANCER SERVICES INTERIM REPORT DECEMBER 1995

EXTRACT FROM A POLICY FRAMEWORK FOR COMMISSIONING CANCER SERVICES

GENERAL PRINCIPLES

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

i) All patients should have access to a uniformly high quality of care in the community or hospital wherever they may live to ensure the maximum possible cure rates and best quality of life. Care should be provided as close to the patient's home as is compatible with high quality, safe and effective treatment.

ii) Public and professional education to help early recognition of symptoms of cancer and the availability of national screening programmes are vital parts of any comprehensive programme for cancer care.

iii) Patient, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards.

iv) The development of cancer services should be patent centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important.

v) The primary care team is a central and continuing element in cancer care for both the patient and his or her family from primary prevention, pre-symptomatic screening, initial diagnosis, through to care and follow up or, in some cases, death and bereavement. Effective communication between sectors is imperative in achieving the best possible care.

vi) In recognition of the impact that screening, diagnosis ad treatment of cancer have on patients, families and their carers, psychosocial aspects of cancer care should be considered at all stages.

vii) Cancer registration and careful monitoring of treatment and outcomes are essential.