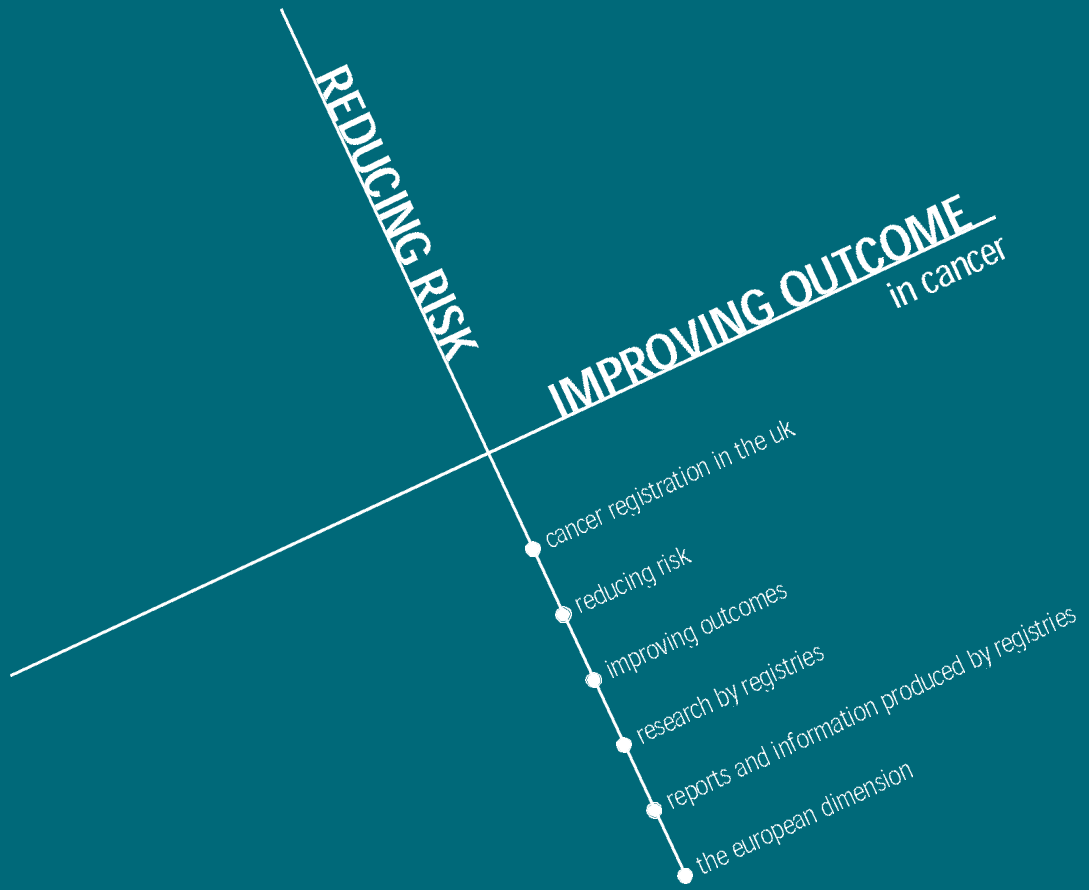


united kingdom association of cancer registries

About this booklet

This booklet explains the work of cancer registries and their contribution to cancer control.

It demonstrates what UK cancer registries can provide for the ultimate benefit of cancer patients, both to reduce risk and to improve outcomes.

It also demonstrates the value for money to the NHS provided by cancer registries.

A short version is available suited to lay readers.

Acknowledgements

The editor would like to acknowledge the many contributions from the Directors and staff of all the UK registries; and particular thanks for contributions from Dr Max Parkin of IARC, Dr Ravi Maheswaran of SAHSU, Dr Michael Jones of the London School of Hygiene and Tropical Medicine, Dr John Osman of the Health and Safety Executive; and to Ms Hatty Lugg for typing the first drafts and collating the graphics. Funding for the collation of the registries' contributions and printing of the booklet was provided by the UKACR.

© United Kingdom Association of Cancer Registries 1998

Editor
CMJ Bell on behalf of the UKACR

Contents

Preface

The UK Association of Cancer Registries (UKACR) was asked by the national Advisory Committee on Cancer Registration (ACCR), when it was constituted in 1997, to produce this booklet to illustrate the work of cancer registries and their contribution to cancer control and cancer policy.

The brief was that the booklet should be aimed at NHS managers and clinicians, civil servants at the Department of Health, politicians, and others with a special interest in cancer. The contents should illustrate what UK cancer registries do, both to reduce cancer risk in the general population and to improve outcomes for cancer patients. This booklet aims to show how registration data are used in the control of cancer; improving care and outcome; helping to plan and manage cancer services efficiently and effectively; monitoring advances in the treatment of cancer; and comparing clinical effectiveness between districts and regions in the UK. Our brief included demonstrating the value for money to the NHS provided by cancer registries.

The booklet has been compiled for the UKACR by Janine Bell on behalf of its scientific sub-group, the Cancer Surveillance Group, which represents the information, research and cancer intelligence functions of the registries. All registries in the UK have contributed to the compilation. We have attempted to represent the range and diversity of uses of cancer registration data.

Tom Davies
Director, East Anglian Cancer Registry

1 Cancer registration in the UK

1.1 Cancer policy

Cancer services have been highlighted in recent years, with public, professional, and political concern about their quality. This led to the first comprehensive national cancer policy in 1995 (Calman-Hine[1] in England and Wales, with equivalents in Northern Ireland and Scotland). Implementation is a long term task, and the ability to monitor change is crucial. Cancer registries provide infrastructure and expertise to achieve this goal.

1.2 The national cancer registration system

The UK registries were set up by the NHS in the period 1945-65. Their purpose was to evaluate the risk of, and survival from, cancer. In 1996, a national core contract for England and Wales was issued (NHS Executive letter EL(96)7) which stated: 'the data collected by cancer registries are vital for monitoring cancer incidence and survival. They are of particular importance in monitoring progress in key national policy areas'. The fundamental goal was to create and maintain a comprehensive, accurate, timely and accessible register of cancers suitable for:

- management of resources for prevention, treatment and laboratory services
- commissioning and evaluating services, including screening programmes
- planning and evaluating clinical management and treatment (including clinical audit)
- research into causes of and survival from cancer
- education of professionals and the public.

Thirteen registries give complete population coverage of England, Wales, Scotland and Northern Ireland. The data they collect serve local, national and international information needs.

There is a national minimum dataset, which is collected by all UK registries. These data are compiled as national statistics produced by the Office for National Statistics (ONS) in England and Wales, the Information and Statistics Division (ISD) of the Common Services Agency for the NHS in Scotland, and the Department of Health for Northern Ireland. Each regional registry also collects additional data items to serve richly diverse local information needs. Arrangements in Scotland and Northern Ireland may differ slightly from those in England and Wales described in this booklet.

Several of the registries also contribute to the published international cancer incidence statistics[2] compiled by the International Agency for Research on Cancer (IARC) from a world-wide network of cancer registries. International variations in incidence give clues about the causes of cancer, and represent an important resource for cancer research. IARC has been influential in fostering cancer registration and the development of specialised statistical methods suited to the analysis of large registry datasets.

1.3 Representing the population

Each UK registry is population-based in order that the information gives an unbiased profile of cancer in its catchment population. Cancer registries aim to collect data for all cancer patients whether treated in hospitals - including acute, long-stay, hospices and private - or by general practitioners.

Comprehensive population-based coverage is essential for public health statistics, needs assessment and service planning. An unbiased sampling frame is also essential for the scientific validity of research studies on cancer in the population. The regional cancer registries in the UK cover a population of 55 million people and register over 200,000 cancers each year, providing powerful comparative data even for rare cancers. The USA and many European countries are aiming to increase the proportion of their populations covered by cancer registration, in order to monitor political strategies.

1.4 Services offered by cancer registries

The main users of registry services

The registries have a wide range of users. All registries in England and Wales supply data to ONS for national statistics. Their other main users are:

- Health Authorities and Health Boards, particularly Directors of Public Health
- Cancer clinicians
- Cancer researchers
- International Agency for Research on Cancer
- NHS Executive Regional Offices.

The main services provided by registries

The services offered to users by registries differ from region to region. Many of the services below (Figure 1) are offered as a core function, free to the user.

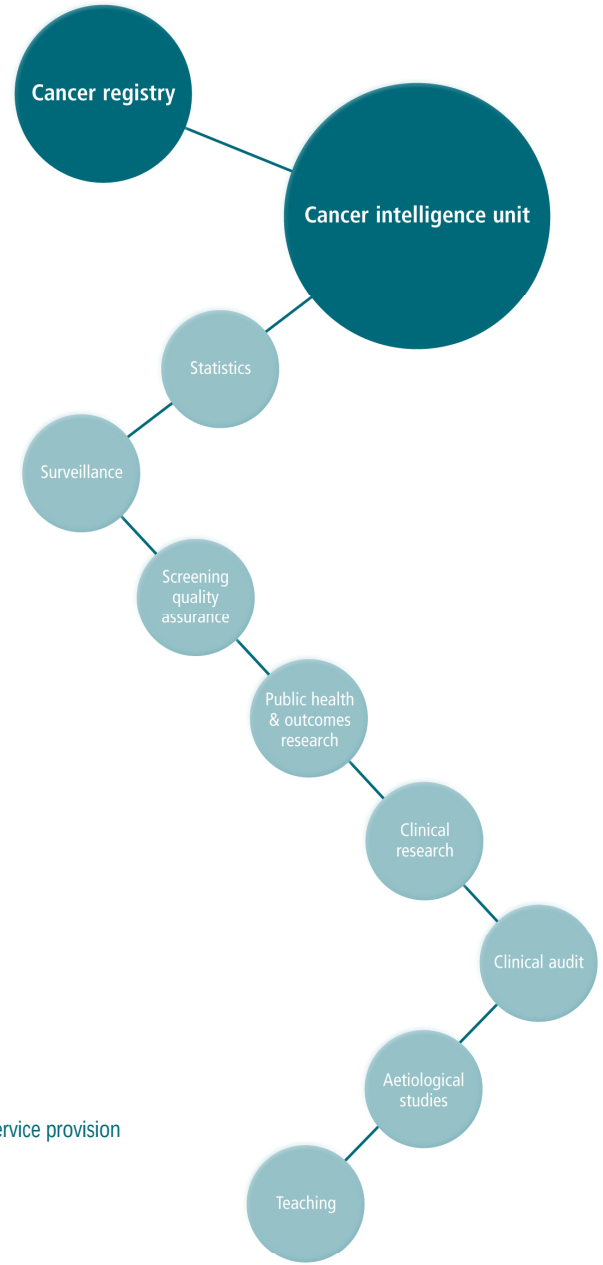


Fig 1 Registry service provision

The release of information is subject to stringent confidentiality rules, which depend on the type of data, the purpose, and the user.

Services include:

- Published reports on cancer in the region (which may include incidence, prevalence, survival)
- Data for evaluation of NHS screening programmes for breast and cervical cancer
- Data for specialist cancer registers such as the National Registry of Childhood Tumours in Oxford
- Customised analyses and reports
- Descriptive statistics and mapping
- Research analyses (case-control or cohort analyses; multivariate modelling; spatial data analyses and geographical information systems)
- Customised datasets – aggregated data or appropriately anonymised individual records for research
- Death information to assist clinicians with outcomes research
- Cancer information for genetic counsellors
- Cancer research – joint working with academic and clinical researchers
- Advice on design, analysis and interpretation of research studies using registry data
- Help with grant applications and publications for joint research studies
- Advice on access to data, confidentiality procedures, and ethical committee protocols
- Training for specialists in public health, oncology and cancer nursing
- Lectures and seminars for clinicians, academic researchers, nurses, clinical coders and medical undergraduates
- Advice on classification, coding and validation of cancer data for trusts and health authorities
- Customised data collection services (eg for haematology networks, screening QA and audit)
- Support for clinical trials
- Support for clinical audit.

Types of data available

The regional registries have databases spanning thirty years or more, typically covering cancers diagnosed since 1960. These databases represent a priceless resource for epidemiological research.

For each registered tumour, the current dataset describes:

- the person – age, sex, postcode of residence
- the tumour – site, histology, date of diagnosis and, for some sites, the stage of disease
- the treatment – hospitals (NHS and private), consultants, and treatment modalities, for in-patients, day-cases and outpatients
- death – date, cause, place.

Cancer Intelligence

Analysis of the data has become known as the cancer intelligence function of the registry. Specialised statistical methods are often required for such large, population-based datasets. Cancer intelligence work links registries with other parts of the health service which aim to evaluate the effectiveness of public

health activities, such as screening, health promotion and (Calman-Hine) re-organisation of cancer services. The complexity of the analyses varies enormously: initial descriptive analysis is followed up frequently by analytical studies to investigate specific questions.

Descriptive studies may examine incidence, mortality, prevalence and survival and their relation to socio-economic factors, tumour characteristics, geographical area and health service factors. Trends and projections or forecasting techniques can be used. Ethnic group and deprivation scores may be added to the original dataset.

Analytical studies examine questions generated by descriptive observations or laboratory studies:

- causation (aetiology), epidemiological studies
- prevention – screening, health promotion
- clinical effectiveness – use and effectiveness of treatment, health services research
- organisation of cancer services – referral patterns, patient flows, comparative performance measures, resource usage, palliative care
- outcome – survival, quality of life, patient satisfaction.

Readers considering using registry data may like to consult the Cancer Registry Handbook[3] which gives a more detailed description of the dataset, the methods of data collection, the research uses of cancer registry data, and the guidelines on confidentiality.

1.5 Value for money

How much does the national cancer registration scheme cost and does it represent value for money to the NHS?

The cost of cancer registration in 1996 was between £10 and £20 per cancer patient in the UK, less than the cost of one chest x-ray. This small price gives information of immense value–as illustrated in this booklet. National coverage provides full and unbiased statistics on cancer in the UK, and permits comparisons between regions within the UK and over time. Registry information is vital for monitoring progress in key national policy areas.

1.6 Confidentiality

The registry databases contain confidential information on millions of people, compiled over several decades. The security and confidentiality arrangements are the prime responsibility of the directors of the registries. Recently updated principles and procedures are available from the cancer registries.[3]

All the registries follow stringent procedures to safeguard the security and confidentiality of registration data. All databases are registered under the Data Protection Act. Release of data follows nationally agreed guidance and follows the European directive on confidentiality.

1.7 Improving performance

The UK registries have an active programme to improve quality and performance. National recommendations were drawn up by the UKACR in 1998. New initiatives such as links to NHS Net (in South & West) and linkage to pathology systems (eg the Cancer Registry Online Pathology Systems (CROPS) project in Wales) are being evaluated.

2 Reducing risk

The most satisfactory and generally most cost-effective method of cancer control is through primary prevention. This requires a sound knowledge of the causes of human cancer, and of the effectiveness of programmes of primary prevention to reduce exposure to carcinogens or enhance resistance to them. For the purposes of prevention, 'causes' need only to be described in terms of environmental agents (such as tobacco) or human behaviours (such as smoking or sun-bathing). Provided exposure to the 'cause' is modifiable, cancer control can be achieved even if the precise causal mechanism is not understood. Cancer registries have a long history of contributing to epidemiological research into causes of cancer and evaluating primary prevention programmes.

2.1 Describing variations in cancer risk

Using registry data alone, it is possible to study differences in cancer risk between different sub-groups of the population.

Incidence

The risk of developing cancer is estimated from the incidence rate - the number of new cases in a given year divided by the population at risk in the area. The incidence varies greatly by age, so age-specific rates are calculated, normally for each 5-year age group. The total incidence is usually standardised to a particular age structure, such as that of the European or World standard population. This gives the age standardised incidence rate.

Comparisons of age standardised incidence rates between countries have provided many important clues to the causes of cancer. Clues provided by descriptive studies need to be followed up by analytical research in order to determine accurately the causes, which may include socio-economic factors and ethnicity, as well as environmental, diet, lifestyle and occupational exposures.

Mortality

Mortality rates are readily available official statistics, which provide a 'second-line' estimate of risk, useful for comparison with incidence. Mortality rates are a 'fuzzy' measure of risk because they depend on both incidence rates and survival. Mortality is a reasonable guide to risk for highly fatal cancers such as those of the lung and oesophagus. Incidence rates are a much better measure of the risk of developing most cancers, provided the cancers are fully ascertained and accurate information is collected.

Deprivation

Registries can group patients by deprivation score, assigned by linking postcode of residence to census data. The West Midlands registry, for example, has shown that cancer risk can vary significantly according to deprivation score. In 1988-92, the incidence rates for breast cancer were 14% higher in Townsend category 1 (most affluent) compared with category 5 (most deprived); the incidence of lung cancer was 47% lower in the most affluent compared to the most deprived group, for both sexes. Merseyside and Cheshire Cancer Registry has used census based 'superprofiles' to show similar effects.

Ethnic origin

Ethnic origin has been collected as part of the national cancer registry minimum dataset since 1993, and in the NHS Contract minimum dataset since 1997. For earlier registrations, it may be possible to identify certain ethnic groups, such as South Asians, because their names are so highly specific. A name algorithm was used to categorise registrations for 1990-92 from a number of English regions (Thames, Trent, West Midlands, Yorkshire). The cancer risks are dramatically different by ethnic group[4], as shown in the box (right).

Geographical area

Incidence rates can be calculated for any geographical areas for which official population figures are available, such as health region, health authority, or local authority. The risk of some cancers varies markedly between regions. Figures 2 and 3 show the risk of two cancers which affect young males – testicular cancer and Hodgkin's disease[5].

The Scottish Cancer Atlas[6] showed a high risk of colorectal cancer in the Highlands, suggesting a possible link with diet – perhaps restricted access to fresh fruit and vegetables.

Acute lymphoblastic leukaemia (ALL) is the most common of childhood cancers. Recent research[7] has shown that childhood leukaemia often increases in incidence when individuals from different areas come together (population mixing). Such increases suggest that an infectious agent or agents may be a cause of ALL. Stiller and Boyle[8] found a significant variation in risk

Age-standardised annual incidence rates per 100,000 for five selected cancer sites, by ethnic group, for residents in English regions diagnosed 1990-92

		Ethnic group	
	Cancer site	Asian	Non-Asian
Males	Hypo-pharynx	2.0	0.6
	Colon	7.4	18.6
	Lung	30.1	58.1
	Prostate	16.7	29.0
	Bladder	8.4	19.2
Females	Mouth	2.8	0.7
	Colon	4.2	14.9
	Liver	2.4	0.9
	Lung	6.9	21.6
	Breast	46.6	72.6

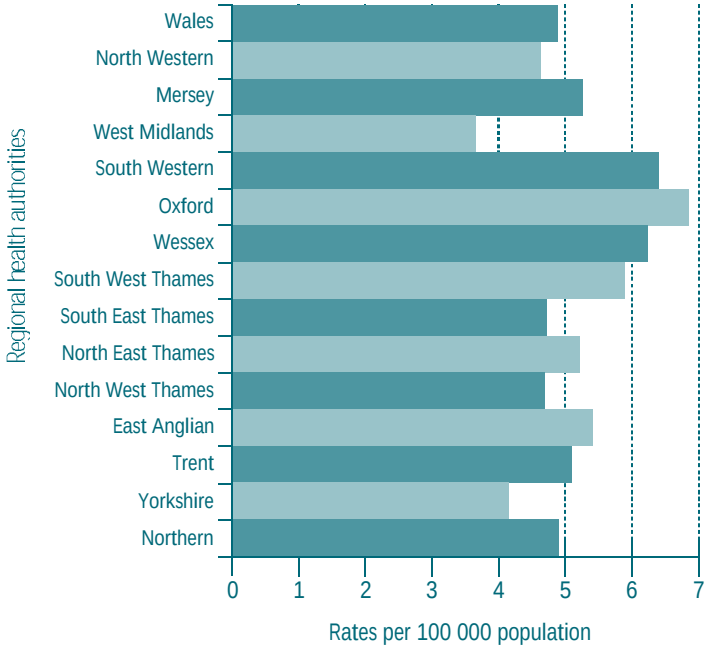


Fig 2 Age standardised incidence rates per 100 000 of newly diagnosed malignant neoplasms of the testis, 1990

Fig 3 Age standardised incidence rates per 100 000 of newly diagnosed cases of Hodgkin's disease in males, 1990

among the 403 local authority districts of England and Wales: the incidence of ALL at ages 0-4 years was 27% higher in districts with high levels of population mixing compared with districts with low levels.

Mapping of cancer incidence and cluster investigation

Contributed by Dr Ravi Maheswaran, Small Area Health Statistics Unit, Imperial College, London

Examination of the geographical variation of disease is one of the classical approaches to identifying clues about the causation of disease. Mapping of cancers in England and Wales dates back to the nineteenth century and over the years has raised important questions about the causes of cancers and routes of exposure, particularly in relation to environmental factors. Studies are usually carried out at a broad geographical scale but these have their limitations. Recently, advances in computational and statistical techniques have permitted mapping and analysis at a small area level eg electoral wards and enumeration districts. The Small Area Health Statistics Unit (SAHSU) has brought together expertise in spatial statistics, geographical information systems and large database computing to carry out small area studies on a national scale. SAHSU is a government-funded unit and its remit includes the investigation of disease near sources of environmental pollution and the study, more generally, of disease variation across small areas of the UK.

Data collected by cancer registries are a valuable resource for examining geographical variations in disease incidence. Geographical studies can be carried out at different levels of complexity. The simplest is a descriptive study, mapping the risk of cancer in different areas and quantifying the extent of variation in risk. At the small area level, adjustments need to be made to take into account the random variation in disease risk due to the small number of cases occurring in small geographical areas. At a more sophisticated level it is possible to look for geographical clusters of cancers, although this is methodologically difficult. Analytical studies can be carried out to examine associations between possible risk factors and cancer incidence. Possible risk factors may be a point source such as an industrial plant or a risk 'surface' such as air pollution.

Time trends in cancer risk

Time trends in incidence, suggesting that the population is exposed to new risk factors, have been observed for testicular cancer, adenocarcinoma of the oesophagus and adenocarcinoma of the cervix. The incidence of adenocarcinoma of the cervix is one-tenth that of squamous carcinoma, but while the overall incidence of cervical carcinoma is declining, adenocarcinoma has increased[9]. In East Anglia[10] the peak age has become progressively earlier in successive birth cohorts (Figures 4 and 5).

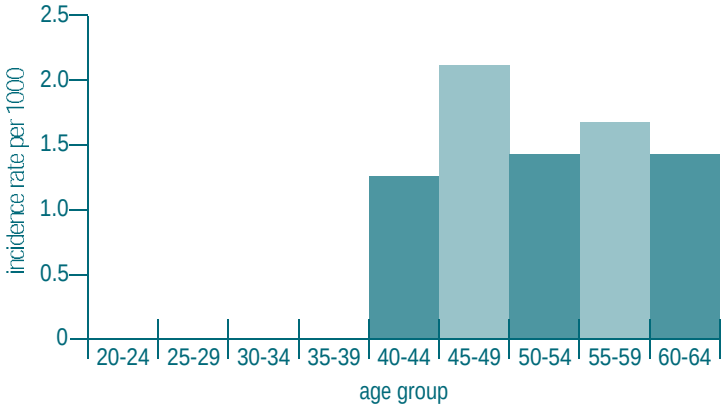


Fig 4 Annual age specific incidence of adenocarcinoma of the cervix (1930-34 birth cohort)

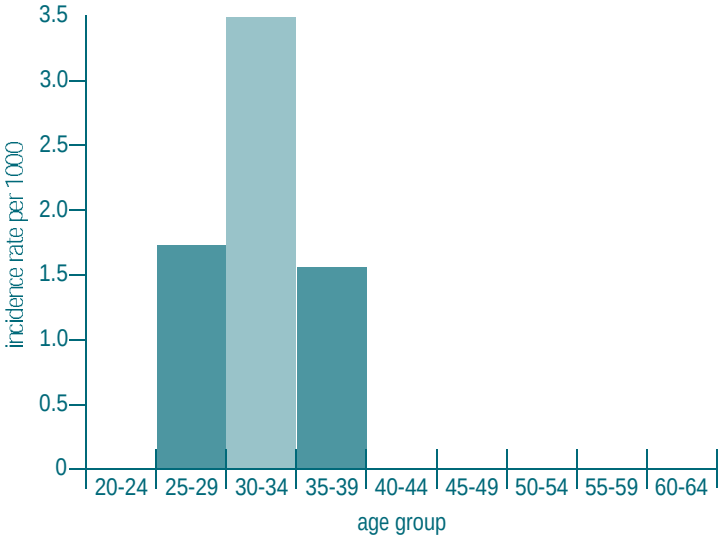


Fig 5 Annual age specific incidence of adenocarcinoma of the cervix (1955-59 birth cohort)

2.2 Identifying risk factors

The most widely used epidemiological techniques for identifying risk factors are case-control and cohort studies. These methods are generally accepted – for example by the IARC Monographs programme[11] – as providing the most powerful evidence of causality. The risk of cancer in a given individual depends on many factors, both inherited and environmental. The principal causes of cancer deaths[12] are cigarette smoking and diet, followed by reproductive and sexual behaviour, occupational exposures and geophysical factors such as cosmic rays and ultra-violet light.

Cancer registries are very frequently used to identify cases for case-control studies and to determine the outcome in prospective cohort studies aiming to quantify the risk of specific exposures. Population-based cancer incidence rates from cancer registries are essential to such cohort studies.

Childhood cancer

While cancer is primarily a disease of old age and childhood cancers are fortunately uncommon, they cost a great deal in human suffering, disability and life years lost. Cancers account for 18% of deaths in the 1-14 age group, second only to accidents. There are around 1200 new cases per year in this

age group. In order to facilitate research on childhood cancers, there is a National Registry of Childhood Tumours which is maintained and extensively used by the Childhood Cancer Research Group at Oxford (see the research publications in Chapter 4).

The UK Childhood Cancer Case-Control Study is a major case-control study including cases of leukaemia and other cancers diagnosed at ages 0-14 in Britain, and identified through paediatric oncology centres and cancer registries. The study is designed to test a number of hypotheses about the causes of childhood leukaemia and other cancers. Data are being collected on many factors including exposure to ionising and non-ionising radiation, and chemical, viral and genetic factors.

Risks following cancer treatment

So many cancer patients now survive for many years that clinicians need to consider the long-term effects of the intensive regimes used to conquer the cancer. The largest study of the risk of bladder cancer after chemotherapy and radiotherapy for ovarian cancer[13] involved eleven registries from around the world. The results showed that ovarian cancer patients having both radiotherapy and chemotherapy had a five times increased risk of developing bladder cancer.

Genetic risk

Cancer registries are a unique resource for genetic research. Registries can be used to systematically identify subgroups and individuals at high risk of cancer – those with cancer at a young age, with rare cancers, or with multiple

A national nested case-control study of second cancer after tamoxifen treatment for breast cancer in Britain

Contributed by Dr Michael Jones, London School of Hygiene and Tropical Medicine

Tamoxifen is a widely used treatment for breast cancer, and current trials to assess its prophylactic use in healthy women without cancer may lead to large-scale use in the general population. There is, however, evidence of a risk of endometrial cancer in relation to tamoxifen treatment, a potential risk of bowel cancer and theoretical reasons why risks of ovarian cancer at premenopausal ages and liver cancer might be raised. This study seeks to provide valuable data on potential long-term risk of these second cancers and hence quality of life which could be expected from those taking tamoxifen.

The cases in the study are women developing cancer of the endometrium, ovary, liver, colon or rectum after a breast cancer diagnosed in the period 1976-95, when tamoxifen was used for treatment of breast cancer. The cases are being identified through the regional registries, and more than 1700 cases are expected. Matched controls (over 2000) are also being obtained from the registries.

A project of this size is only possible because of the national coverage of cancer registration in Britain. Indeed, this will be the largest study of its type in the world.

cancers. Geneticists are then able (subject to ethical approval) to carry out research on the family history and the biological tissue of these individuals. Registries can also be used to monitor cancer incidence in high-risk groups in the population, such as those with familial polyposis coli.

All the UK registries are also used by the regional genetic counselling services to trace and confirm cancer in relatives of patients being counselled, subject to consent as given in the confidentiality guidelines.

Occupation and cancer risk: uses of cancer registration data

Contributed by Dr John Osman , Health and Safety Executive (HSE)

It has been estimated that between 2% and 8% of all cancers are occupational in origin[12]. Exposure to occupational carcinogens may be more readily amenable to control than carcinogen exposure in other settings, with good prospects for prevention. The cancer registration system contributes to the identification and control of occupational causes of cancer in several ways.

Firstly, data available within the system can be used in occupational cohort studies and case control studies of putative occupational carcinogens. Between 1960 and 1993 the Office for National Statistics collaborated with researchers on 130 occupational studies[14], and cancer registration data were sought for many of these. Secondly, it has now been established that the occupational data recorded by the cancer registration system can be reliably used to identify known associations between cancer and employment in specific types of work[15]. This means that it can be used alongside mortality data to generate new hypotheses on the role of occupational exposure in the causation of cancer, and to examine hypotheses generated by other data.

As improvements in treatment lead to increasing survival from cancer, registration data will become increasingly important in monitoring the effectiveness of legislative and other controls on occupational exposures.

Occupational carcinogens are one focus of the HSE's current 'Good Health is Good Business' awareness campaign. Cancer registration data make a valuable contribution to HSE's preventive activity.

HIV

HIV infection leads to an increased risk of cancer, including Kaposi's sarcoma and other skin cancers, and cerebral lymphomas. The cancer risks associated with HIV infection have not yet been fully evaluated. A study is planned in Scotland to address this through linkage between the HIV register and the cancer registry. This will inform planners of the public health impact of the disease and service needs of those living with HIV disease.

2.3 Reducing risk

Health promotion

The effectiveness of health promotion campaigns, for example 'mole watching' to detect melanomas of the skin early, can be monitored by registries. Oxford Cancer Intelligence Unit is actively involved in their local campaign, and has detected a shift to earlier stage at presentation of melanomas.

National policy targets

Registries are being used extensively for monitoring policy targets such as 'The Health of the Nation' and 'Our Healthier Nation'.

The target to reduce mortality from lung cancer by 30% in men and 15% in women by the year 2010 was going to be especially difficult to meet in the Mersey region[16].

Lung cancer death rates per 100,000 at ages 0-74 in Mersey Region, 1990

	Mersey	England & Wales	HoN target
Men	75.4	60.0	42.0
Women	32.4	24.1	20.5

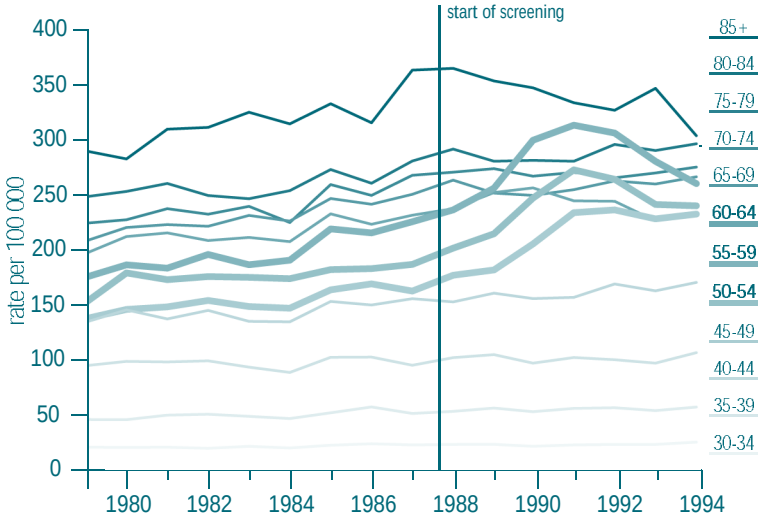


Fig 6 Age specific incidence of breast cancer, E&W, 1979-1994

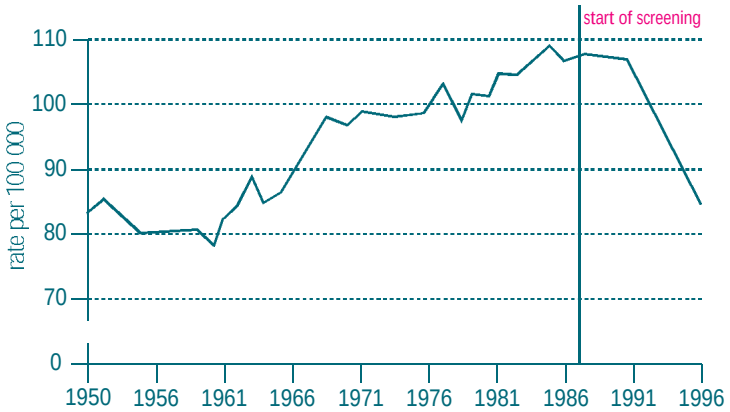


Fig 7 Age standardised* breast cancer mortality rates ages 55-69 E&W, 1950-1996

* European standard population

The target to reduce mortality from breast cancer by 25% in women aged 55-69 years group by the year 2000 is likely to be met nationally if current trends continue.

The reported incidence of breast cancer has risen steeply since 1988, mainly in the screening age group, as a result of the NHS Breast Screening Programme. An encouraging fall in mortality, has been observed in the same period in all age groups (Figures 6 and 7)[17]. The contrast between the two sets of data highlights the importance of using incidence to monitor risk and mortality rates to monitor the effectiveness of screening.

Evaluation of NHS screening programmes

The cancer registries are vital for evaluating the efficacy of the NHS screening programmes. Four registries (Oxford, South and West, North Western, and West Midlands) have a dual role, hosting the regional Quality Assurance Reference Centre for the NHS Breast Screening Programme.

Cervical screening

Since 1988 all women aged between 20-64 have been invited for screening at intervals of 3 or 5 years. The effects on incidence and outcome can be monitored using the regional registry. Since 1988, screening coverage in Wessex has increased from 60% to 87%; and the incidence of invasive cancer in one part of the region, south-west Hampshire, changed significantly after the screening programme was introduced (as shown in Figure 8)[18].

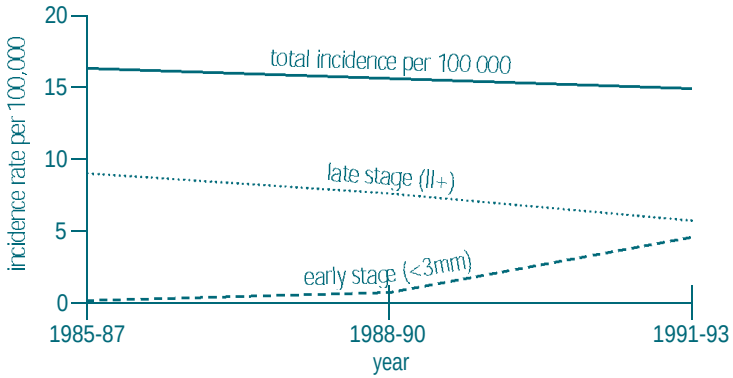


Fig 8 Age standardised annual incidence of early and late stage cervical cancers following increased coverage of cervical screening

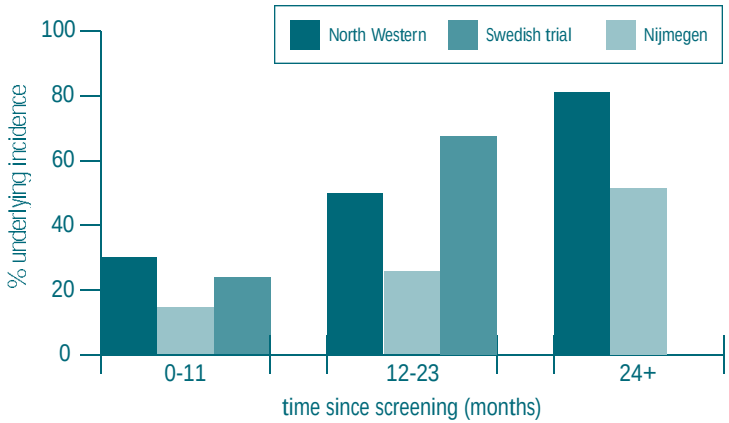


Fig 9 Comparison of interval cancers as a proportion of underlying incidence in the North West, Swedish Two County Trial and Nijmegen screening programmes

Breast screening

Interval cancers – those diagnosed in the (normally three year) interval between two screening episodes, when no cancer was detected at the first of those episodes – are used as a measure of the success or failure of the programme[19]. There is concern that the 3-year screening interval is too long: an evaluation by the North Western regional cancer registry[20] of all breast cancers in the population screened in a 4-year period showed that by the third year after screening the incidence of interval cancers approached that expected in the absence of screening. The North Western regional interval cancer rate is substantially higher than that reported in the Swedish Two County Trial but comparable to data from Nijmegen, Holland, as shown in Figure 9.

An evaluation of the prevalent screening round – women entering the screening programme for the first time – in South East Thames in 1991-92[21] showed that some 48% of breast cancers in the screening age group were screen-detected (Figures 10,11). However, only 19% of breast cancers at all ages were screen-detected, 60% being outside (mainly older than) the screening age range of 50-64 years. The uptake of screening varied with lifestyle - from 74% in the most affluent to 52% in the least affluent areas of Merseyside.

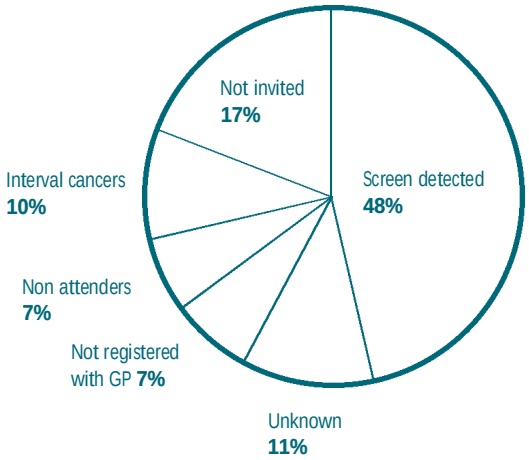


Fig 10 Breast cancers in women aged 50-64 diagnosed in 1991-2, SE Thames

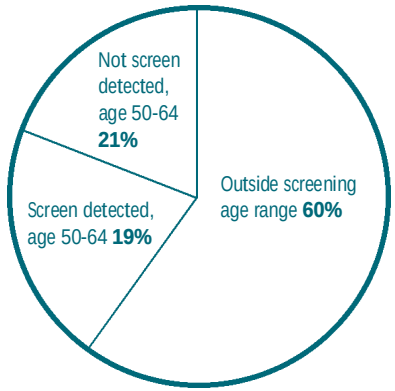


Fig 11 Breast cancers in women of all ages diagnosed 1991-2, SE Thames

3 Improving outcome

3.1 Improving services

The Calman-Hine report in 1995[1] recommended the use of cancer registries to monitor the quality of cancer treatment and specialisation in Engalnd and Wales. Comparable reports were issued for Scotland and Northern Ireland. As a result, over the past three years the UK registries have been increasingly active in region-wide clinical audit projects. Based on experience of many retrospective studies including the EUROCARE study, prospective region-wide audits are now in progress or being set up in several regions:

- Scotland (breast, colorectal, lung, ovary pain-control)
- Thames (breast, colorectal)
- Wessex (colorectal)
- Oxford (breast)
- Trent (breast, colorectal).

The pilot study for the North Thames region-wide audit of breast cancer[22] found significant differences in care between specialist and non-specialist centres in terms of quality of surgery and use of fine needle aspiration (FNA), but few other systematic differences in care.

These audits increase the level of collaboration between registries and clinical practice. They also provide trusts and health authorities with comparable measures of workload and performance. Monitoring outcome of treatment is more complex as illustrated in the next section. Exploratory analysis of survival by hospital treatment for five cancer sites are being produced by East Anglian Cancer Registry in collaboration with trusts.

3.2 Improving outcome

The Calman-Hine recommendations[21] were based on the view that specialisation would improve outcomes. Much of the evidence supporting that view[23] came from cancer registry studies. These studies suggested repeatedly that access to, and quality of multi-disciplinary clinical care explained, in part, the differences in outcome.

Ovarian cancer

Several registry-based studies of ovarian cancer in Scotland and in the North Western region have shown improved survival from management in teaching hospitals, and that treatment by a gynaecologist yields better results than treatment by a general surgeon[24-26]. These studies showed that multidisciplinary therapy yields benefits, which seem to depend more on the treatment than the type of hospital where treatment is delivered. In the West Midlands, survival in women treated by gynaecologists was considerably higher than in women treated by general surgeons (Figure 12).[30]

Cancers of the digestive tract

Large variations between surgeons in outcome of gastric cancer were found in Scotland, with wide variation in the rates of curative resection, perioperative mortality and five-year survival.[27]

Large variations between surgeons have been found in both the care and outcome of colorectal cancer patients.[28] The relative risk of death after curative resection was four times higher for surgeons with the worst results compared with those having the best results.

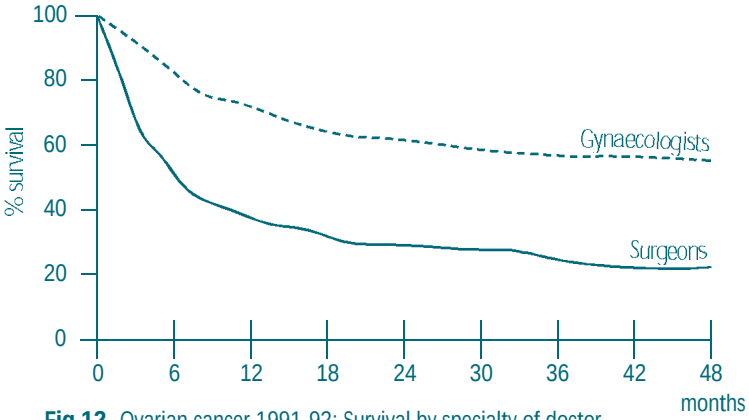


Fig 12 Ovarian cancer 1991-92: Survival by specialty of doctor performing operation

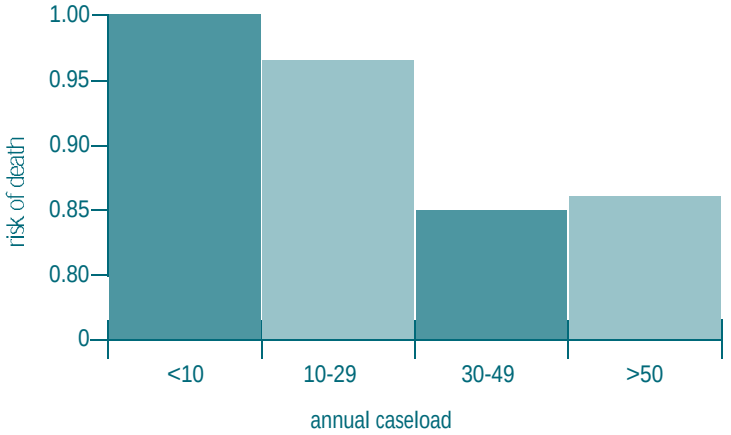


Fig 13 Relative risk of death from breast cancer according to surgeons' caseload (Yorkshire)

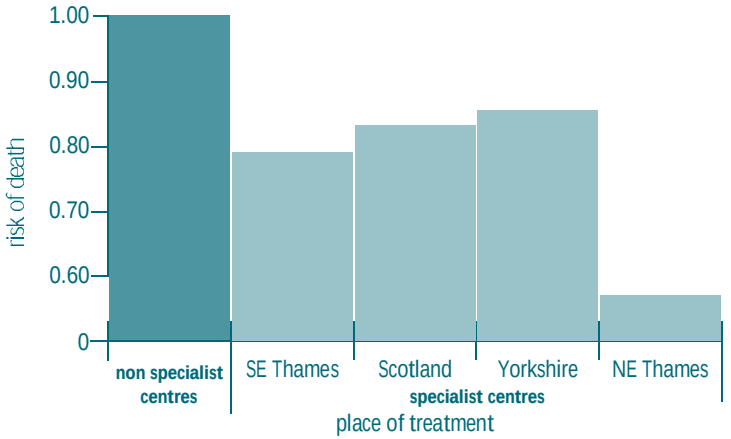


Fig 14 Relative risk of death from breast cancer in specialist centres vs non-specialist centres

In Finland, Hakama et al[29] estimated that management of patients in a specialist teaching hospital increased the chances of survival from colorectal cancer by 10-15%. A study by North Western cancer registry has shown that a specialist surgeon in coloproctology can achieve similar results in a teaching hospital or a non-teaching hospital.[30] The EUROCARE study found that the proportion of patients having surgical resection correlated positively with five year survival. Survival ranged from 58% in Estonia to 92% in Tarn.[31]

Breast cancer

Large variations in care and outcome were found for breast cancer patients in Yorkshire.[32] Surgeons who had an annual caseload of more than 30 patients had significantly better results compared with those treating fewer than 10 patients. Patients of high caseload surgeons had a 15% lower risk of death (Figure 13).

Other population based studies in South East Thames, North East Thames, and Scotland[33-35], have provided further evidence of better outcome in specialist centres, for patients diagnosed in the 1980s, as shown in Figure 14.

Childhood cancer

In 1960, the age-standardised annual mortality rate for neoplasms among children aged 1-14 in England and Wales was 86 per million. By 1992, this mortality had more than halved to 37 per million. This dramatic reduction in mortality reflects an equally dramatic improvement in survival rates for children with cancer.

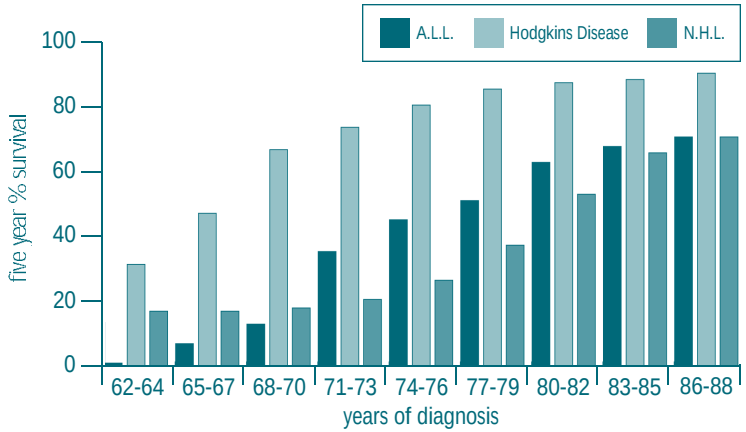


Fig 15 Improvements in survival from childhood cancers

Towards the end of the 1960s the five-year survival rate for childhood leukaemia was still only around 10%. Retinoblastoma and Hodgkin's disease were among the few cancers with a survival rate of over 50%. By the late 1980s, as shown in Figure 15, (ALL), Hodgekins disease, non-Hodgkins lymphoma (NHL) had improved dramatically.

These increases in survival were directly related to advances in treatment, but there were also major changes in patterns of referral. At one time most children were treated at local hospitals and there were few clinicians specialising in paediatric oncology. Treatment has gradually become more centralised and larger numbers of children have been entered in national and international clinical trials and studies. For several types of cancer, survival has been found to be better among children who were treated at specialist centres or who were entered in national or international clinical trials.

As a consequence of improved survival, there are now more than 10,000 adult survivors of childhood cancer, equivalent to the population of a small town. Several registry-based studies have looked at these survivors, whether they are really cured, their quality of life, their risk of another cancer, the probability of them having children of their own and the health of those children.

Those children who survive for five years or more do seem to be cured, with only a 10% risk of death related to the cancer in the subsequent 10 years, and a small (4%) risk of another malignancy within 25 years. The health of the survivors' children seems good, with no evidence of congenital malformations or of cancers, except for retinoblastoma in the children of patients who had the genetic form of retinoblastoma.

For more detail about childhood cancer survival, see Stiller's chapter entitled 'Aetiology and Epidemiology' in the recent reference book 'Paediatric Oncology: Clinical Practice and Controversies'[36].

3.3 Needs assessment

The burden of cancer

Health authorities are responsible for providing the health needs assessment for their population. In order to discharge this duty, they need information on the burden of cancer – the numbers of new incident cases arising in the population, and also the number of prevalent cases – that is the numbers diagnosed in previous years that are still alive. The burden of prevalent cases permits needs assessment for palliative care and rehabilitation services.

Prevalence estimates are difficult to make, but are important for commissioning services. The various methods for estimating prevalence are being tested at Trent Cancer Registry and through the international Europreval project starting in 1998.

The East Anglian Cancer Registry, commissioned by the Cancer Relief Macmillan Fund, recently forecast that in twenty years time – in 2018 – incident cases will have increased by 56% and the prevalent cases by 68%[37]. The large increase in prevalence was attributed to better survival due to new treatments, as well as greater longevity with more old people in the population. This forecast was based on a number of assumptions, but has huge implications for the NHS.

Delivery of services

Registries can provide information on the number of new cancers seen in each Trust and the number of patients by broad treatment modality and per consultant. Such data have been used in implementing the Calman-Hine re-organisation of cancer services. Information on resource usage by patient, and by cancer type can be obtained by linking registry data (patient-based) with Hospital Episode Data (HES or 'Korner' data). The reports listed for the South and West Cancer Intelligence Unit in Chapter 5 reflect the demand for such data.

Access to care

Equity of access to high quality of care is a central tenet of the Calman-Hine recommendations. There is concern that access is more difficult for ethnic minorities, the elderly, and the deprived. Increasing specialisation and centralisation of care may increase the divide. Registry data can be used to identify and study certain ethnic sub-groups, and people resident in economically deprived areas, or living a long distance from an appropriate hospital.

3.4 Measuring outcomes

Survival

The registries record the date of death of all people registered with cancer and can compute survival. The registries routinely receive notification of all deaths where cancer is mentioned on the death certificate, through cooperation with

the government statistical services (ONS in England and Wales, GRO in Scotland and in Northern Ireland). The government agencies also provide non-cancer death information for registered patients: ONS flags patients at the NHS Central Register and the GROs provide data electronically which permits record linkages.

Relative survival is the statistic most often used, as this adjusts for competing causes of death to give an estimate of the probability of death from the cancer alone. This is usually presented as the percentage of patients surviving five years (or two years for more rapidly fatal cancers). Trent Cancer Registry has developed user-friendly software to permit easy computation of relative survival rates.

Survival outcome is extremely important information for health commissioners and patient organisations, as well as the treating clinicians. The calculation of survival rates in selected groups of patients, such as the patients attending a particular hospital, should be treated with great caution because it is extremely difficult to adjust for all the factors that may be influencing the survival outcome.

Figure 16 compares the relative survival rates for colorectal cancer in health authorities in the North Thames Region in 1992[38].

The EUROCARE study[39] was a major international multi-registry collaboration, which showed large differences in survival between European countries (Figure 17). Survival in the UK was worse than the European average for most common cancers. While this may in part be due to more complete follow-up or linkage with death information, the results supported the need for initiatives to improve survival in the UK.

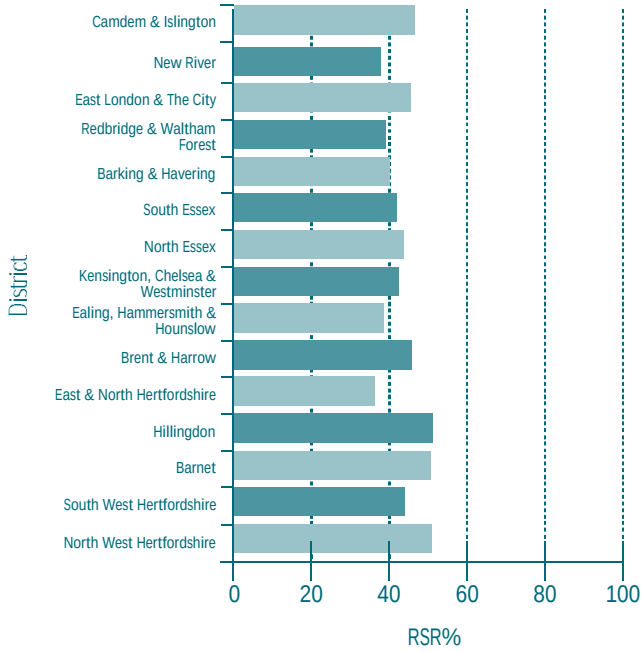


Fig 16 Relative survival rate (RSR) at five years by district in North Thames

3.5 Factors which affect survival

The length of survival after a diagnosis of cancer depends on many factors: the conventional prognostic factors such as aggressiveness of the disease, early or late stage at detection and the patient's age and sex. Healthcare factors such as quality and efficiency of treatment may play a major role.

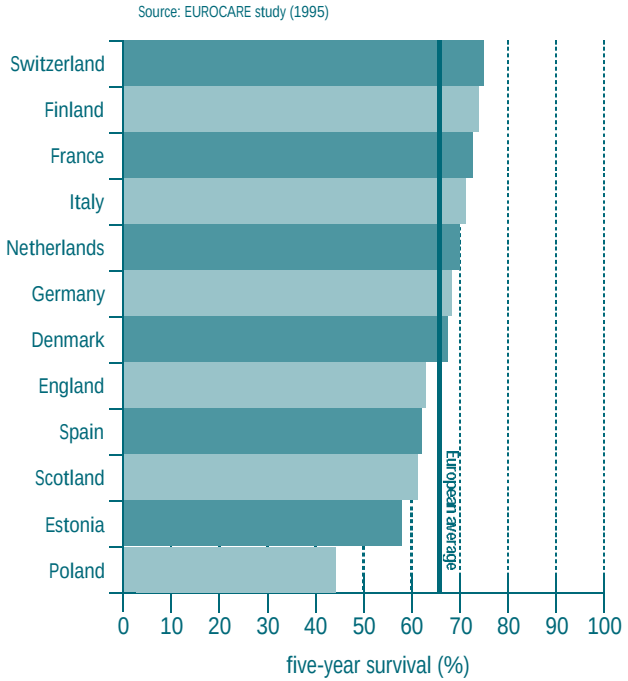


Fig 17 Breast cancer in Europe: five year survival (%) patients diagnosed 1978-85 and followed up to 1990

Socio-economic factors such as income, education, and social support may be important, as well as host factors – the patient's own psychological and immune response to the disease. In addition, artefactual differences in survival rates can occur due to differences between populations in diagnostic criteria, screening intensity, or registration quality.

Breast Cancer survival in Scotland

Deprivation category	5-year survival %
1 (affluent)	66
2	65
3	60
4	59
5	55
6	56
7 (deprived)	55

An in-depth study including analysis by multivariate methods is therefore essential in order to interpret correctly any survival differences observed in descriptive statistics.

The effect of deprivation was demonstrated in the West of Scotland[40]. The age-adjusted five-year survival from breast cancer was 11% lower in the most deprived group compared with the most affluent. They used a measure of deprivation based on place of residence. The results above are for histologically verified breast cancers diagnosed in 1980-87, followed up to 1993. They showed that deprivation appeared to influence the survival rate at five years after diagnosis, despite there being no difference between deprivation categories in terms of established prognostic factors such as tumour stage.

3.6 Quality of life

Cancer patients deserve to have a reasonable quality of life, and may need help in coping with psychological and physical aspects of life after a diagnosis of cancer. For example, they may experience anxiety, loss of energy, or have to cope with the disfigurement caused by the removal of a head and neck cancer, deal with a colostomy 'bag' after colorectal cancer, or impotence or incontinence after prostate cancer. Measures of quality of life are being developed and tested at the Northern and Yorkshire registry, and are in use by the Scottish Cancer Therapy Network. These data will be particularly valuable for patient representative groups such as Cancer Relief Macmillan Fund, CancerBACUP, Cancerlink, and the National Cancer Alliance.

4 Research by registries

Papers published in peer-reviewed journals are an accepted measure of research activity. This chapter attempts to illustrate the formidable resource for research which registries represent, using the output between 1994-97 from seven of the registries. The total output from all UK registries exceeded 200 published papers in four years. In addition, there are papers resulting from multi-registry national and international collaborations, presented in the final section of this chapter.

The research activity of a registry depends critically on the level of core resources allocated for research, the skills of its research staff, and the links with and accessibility of the registry to academic departments of public health, oncology and epidemiology.

Depending on local arrangements, registry research may be in-house or collaborative, as illustrated by the authorship of the following publications which make substantive, original use of the registry data, or represent a substantial commitment from registry staff. Reports and fact-sheets are not included – these are described in Chapter 5.

Childhood Cancer Research Group

1994

Bithell JF, Dutton SJ, Draper GJ, Neary NM. Distribution of childhood leukaemias and non-Hodgkin's lymphomas near nuclear installations in England and Wales. Br Med J 1994; **309**: 501-505.

Draper GJ, Kroll ME, Stiller CA. Childhood Cancer in Trends in Cancer Incidence and Mortality. Cancer Surveys 1994; **19/20**: 493-517.

Mann JR, Stiller CA. Changing patterns of incidence and survival in children with germ cell tumours (GCT's). Advances in the Biosciences 1994; **91**: 59-64.

Robertson CM, Hawkins MM, Kingston JE. Late deaths and survival after childhood cancer: implications for cure. Br Med J 1994; **309**: 162-166.

Stiller CA, Eatock EM. Survival from acute non-lymphocytic leukaemia, 1971-88: a population-based study. Arch. Dis Child 1994; **70**: 219-223.

Stiller CA, Chessell JM, Fitchett M. Neurofibromatosis and childhood leukaemia/lymphoma: a population based UKCCSG study. Br J Cancer 1994; **70**: 969-972.

Stiller CA. Population based survival rates for childhood cancer in Britain, 1980-91. Br Med J 1994; **309**: 1612-1616.

1995

Craft AW, Parker L, Stiller C, Cole M. Screening for Wilm's tumour in patients with Aniridia, Beckwith syndrome, or hemihypertrophy. Medical & Pediatric Oncology 1995; **24**: 231-234.

Draper GJ. in The Health of our Children. Decennial Suppplement. B Botting et al (eds.). **10**: 135-147. OPCS, Series DS no.11, HMSO, London, 1995.

Hawkins MM, Draper GJ, Winter DL. Cancer in the offspring of survivors of childhood leukaemia and non-Hodgkin's lymphomas. Br J Cancer 1995; **71**: 1335-1339.

Hawkins MM, Winter DL, Burton HS, Potok MHN. Heritability of Wilms' tumour. J Natl Cancer Inst 1995; **87**: 1323-1324.

Kinlen LJ, Dickson M, Stiller CA. Childhood leukaemia and non-Hodgkin's lymphoma near large rural construction sites, with a comparison with Sellafield nuclear site. Br Med J 1995; **310**: 763-768.

Lyons RA, Monaghan SP, Heaven M, Littlepage BNC, Vincent TJ, Draper GJ. Incidence of leukaemia and lymphoma in young people in the vicinity of the petrochemical plant at Baglan Bay, South Wales, 1974 to 1991. Occupational and Environmental Medicine 1995; **52**: 225-228.

Richardson S, Monfort C, Green M, Draper G, Muirhead C. Spatial variation of natural radiation and childhood leukaemia incidence in the UK. Statistics in Medicine 1995; **14**: 2487-2501.

Stiller CA, Allen MB, Eatock EM. Childhood cancer in Britain: The National Registry of Childhood Tumours and incidence rates 1978-87. Eur J Cancer 1995; **31A**: 2028-2034.

1996

Draper GJ, Sanders BM, Lennox EL, Brownbill PA. Patterns of childhood cancer among siblings. Br J Cancer 1996; **74**: 152-158.

Hawkins MM, Kinner-Wilson LM, Burton HS, et al. Radiotherapy, alkylating agents, and risk of bone cancer after childhood cancer. J Natl Cancer Inst 1996; **88**: 270-278.

Levitt G, Bunch KJ, Rogers CA, Whitehead B. Cardiac transplantation in childhood cancer survivors in Britain. Eur J Cancer 1996; **32A**: 826-830.

Little MP, Muirhead CR, Stiller CA. Modelling lymphocytic leukaemia incidence in England and Wales using generalizations of the two-mutation model of carcinogenesis of Moolgavkar, Venzon and Knudaon. Statistics in Medicine 1996; **15**: 1003-1022.

Stiller CA, Boyle PJ. Effect of population mixing and socio-economic status in England and Wales, 1979-85, on lymphoblastic leukaemia in children. Br Med J 1996; **313**: 1297-1300.

1997

Narod SA, Hawkins MM, Robertson CM, Stiller CA. Congenital anomalies and childhood cancer in Great Britain. Am J Human Genet 1997; **60**: 474-485.

Mott MG, Mann JR, Stiller CA. The United Kingdom Children's Cancer Study Group – the first 20 years of growth and development. Eur J Cancer 1997; **33**: 1448-1452.

Draper GJ, Little MP, Sorahan T, Kinlen LJ, Bunch KJ, Conquest AJ, Kendall GM, Kneale GW, Lancashire RJ, et al. Cancer in the off-spring of radiation workers – a record linkage study. National Radiological Protection Board (Report -R298), Chilton, 1997.

Draper GJ, Little MP, Sorahan T, Kinlen LJ, Bunch KJ, Conquest AJ, Kendall GM, Kneale GW, Lancashire RJ, et al. Cancer in the offspring of radiation workers: a record linkage study. Br Med J 1997; **315**: 1181-1188.

East Anglian Cancer Registry

1995

Day N, McCann J, Camilleri-Ferrante C, Britton P, Hurst G, Cush S & Duffy S. Monitoring interval cancers in breast screening programmes: the East Anglian experience. J Med Screening 1995; **2**: 180-185.

1996

Day NE, Davies TW. Cancer registration: integrate or disintegrate? Br Med J 1996; **313**: 896.

Davies TW, Palmer CR, Ruja E, Lipscombe JM. Adolescent milk, dairy product and fruit consumption and testicular cancer, Br J Cancer 1996; **74**: 657-660.

1997

Stockton D, Davies TW, Day NE, McCann J. Retrospective study of reasons for improved survival in patients with breast cancer in East Anglia: earlier diagnosis or better treatment? Br Med J 1997; **314**: 472-475.

McCann J, Wait S, Séradour B, Day NE. A Comparison of the Performance and Impact of Breast Cancer Screening Programmes in East Anglia, UK and Bouches Du Rhône, France Eur J Cancer 1997; **33**: 429-435.

Gibson L, Spiegelhalter DJ, Camilleri-Ferrante C, Day NE. Trends in invasive cervical cancer incidence in East Anglia from 1971 to 1993, J Med Screening 1997; **4**: 44-48.

Stockton D, Cooper P, Lonsdale RN. Changing incidence of invasive adenocarcinoma of the uterine cervix in East Anglia, J Med Screening 1997, **4**: 40-43.

Badrinath P, Day NE, Stockton D. Seasonality in the Diagnosis of Acute Lymphocytic Leukaemia, Br J Cancer 1997; **45**: 1711-1713.

Merseyside and Cheshire Cancer Registry

1997

Maudsley G,Williams EMI. Variability of skin cancer registration practice in the United Kingdom. J Epidemiol Community Health 1997; **51:** 337-338.

Seddon DJ, Williams EMI. Data quality in population-based cancer registration: an assessment of the Merseyside and Cheshire Cancer Registry. Br Journal Cancer 1997; **76**: 667-674.

Northern and Yorkshire Cancer Registry and Information Service (NYCRIS)

1994

Hall NR, Finan PJ, Ward B, Turner G, Bishop DT. Genetic susceptibility to colorectal cancer in patients under 45 years of age. Br J Surgery 1994; **81**: 1485-1489.

Crawford SM, Atherton F. Lung Cancer: histological aspects of diagnosis in England and the south east Netherlands. J. Epi. & Comm.Health 1994; **48**: 420-421.

Sagar PM, Gauperaa T, Sue-Ling H, McMahon MJ, Johnston D. An audit of the treatment of cancer of the oesophagus. Gut 1994; **35**: 941-945.

Quinn CM, Ostowski JL, Lane SA, Loney DP, Teasdale J, Benson EA. c_erbB-3 protein expression in human breast cancer comparison with other tumour variables and survival. Histopathology 1994; **25**: 247-252.

Muers MF. Pre-operative screening for metastases in lung cancer. Thorax 1994; **48**: 1-2.

Muers MF. How much investigation? in: 'New perspectives in lung cancer.' (eds Thatcher N and Spire S.) BR MED J Publications London 1994; 77-104.

1995

Sainsbury R, Haward R, Rider L, Johnston C, Round C. Influence of clinician workload and patterns of treatment on survival from breast cancer. Lancet 1995; **345**: 1265-1270.

Sainsbury R, Rider L, Smith A, McAdam A. Does it matter where you live? Treatment variation for breast cancer in Yorkshire. Br J Cancer; **71**: 1275-1278.

London NJ, Farmery SM, Will EJ, Davison AM, Lodge JPA. Risk of neoplasia in renal transplant patients. Lancet 1995; **346**: 403-6.

1996

Varghese C, Barrett JH, Johnston C, Shires M, Rider L, Forman D. High risk of lymphomas in children of Asian origin: ethnicity or confounding by socioeconomic status? BJ Cancer 1996; **74**: 1503-5.

1997

Connolly CK, Crawford SM, Rider PL, Smith ADM, Johnston CF, Muers MF. Carcinoma of the bronchus in the Yorkshire region of England 1976-1990: Trends since 1984. European Respirator Journal 1997; **10**: 397-403.

Muers MF, Haward RA. Management of lung cancer. Thorax 1997; **51**: 557-60.

North Western RCR – Centre for Cancer Epidemiology

1994

Lancaster G, Moran A and Woodman CBJ. Towards achieving the health of the nation target for cervical cancer: Accuracy of cancer registration. J Public Hlth Med 1994; **16**: 50-52.

Kehoe S, Powell J, Wilson S and Woodman CBJ. The influence of the operating surgeon's specialisation on patient survival in ovarian carcinoma. Br J Cancer 1994; **70**: 1014-1017.

1995

Woodman CBJ, Threlfall A, Boggis C and Prior P. Is the 3 year screening interval too long? - The occurrence of interval cancers in the National Health Service Breast Screening Programmes' North West Region. Br Med J 1995; **310**: 224-6.

Woodman CBJ, Prior P, Joseph R and Watson A. Prospects for the secondary prevention of colorectal cancer: screening by flexible sigmoidoscopy. J Med Screening 1995; **2**: 71-78.

Dey P, Woodman CBJ. Epidemiology of Cervical Cancer. In: Gynaecologic Oncology: Current Diagnosis and Treatment. Ed. Shingleton et al, Saunders 1995.

Clyma JA, Winter H, Wilson S, Woodman CBJ. Epidemiology of Gynaecological Cancer. In: Scientific Essentials of Reproductive Medicine. Ed. Kitchener H.C. Saunders 1995.

Wilson S, Prior P, Moran A and Woodman CBJ. Is the clinical oncology network (COIN) the answer? J Clin Oncol 1995; **7**: 145-146.

1996

Prior P, Woodman CBJ, Wilson S, Threlfall A. The reliability of underlying incidence rates for assessing the effect and efficiency of screening for breast cancer. J Med Screening 1996; **3:** 1-4.

Woodman CBJ, Coyne J, Baildam A, Singleton J. Management of premenopausal women with primary breast cancer. Br J Surgery 1996; **83**: 1256-1257.

Asbury D, Boggis C, Sheals D, Threlfall A and Woodman CBJ. NHS Breast Screening Programme: Is the high incidence of interval cancers inevitable? Br Med J 1996; **313**: 1369.

Maddock I, Moran A, Teare D, Evans DGR et al. A genetic register for von Hippel Lindau disease. J Med Genetics 1996; **33**: 120-7.

1997

Dey P, Woodman CBJ, Coyne J and Gibbs A. Completeness of reporting on prognostic factors for breast cancer - A regional survey. J Clin Path 1997; **60**: 829-831.

Moran A, Collins S, Evans DGR. Risk of subsequent primary cancers in patients with carcinoma of the ampulla of Vater. Br J Cancer 1997; **76**: 1232-1233.

Threlfall A, Woodman CBJ and Prior P. Breast Screening Programme: should the interval between tests depend on age. Lancet 1997; **349**: 472.

Woodman CBJ, Baghdady A, Collins S, Clyma JA. What changes in the organisation of cancer services will influence the outcome for women with ovarian cancer. Br J Obstet and Gyn 1997; **104**: 135-9.

Scottish Cancer Intelligence Unit

1994

Black RJ, Sharp L, Finlayson AR, Harkness EF. Cancer incidence in a population potentially exposed to Radium-226 at Dalgety Bay, Scotland. Br J Cancer 1994; **69**: 140-143.

Black RJ, Sharp L, Harkness EF, McKinney PA. Leukaemia and non-Hodgkin's lymphoma: incidence in children and young adults resident in the Dounreay area of Caithness, Scotland in 1968-91. J Epidemiol Community Health 1994; **48**: 232-236.

Brewster D, Black RJ, Muir CS. Bladder cancer in Scotland: Recent trends in incidence, survival and geographical distribution. Health Bulletin 1994; **52**: 248-259.

Brewster D, Crichton J, Muir CS. How accurate are Scottish cancer registration data? Br J Cancer 1994; **70**: 954-960.

Dewar JA, Duncan W, Eremin O, Kaye SB, Muir CS, Gould A. The Scottish Cancer Therapy Network: the first year. Health Bulletin (Edinburgh) 1994; **52**: 492-95.

McKinney PA, Ironside JW, Harkness EF, Arango JC, Doyle D, Black RJ. Registration Quality and Descriptive Epidemiology of Childhood Brain Tumours in Scotland 1975-1990. Br J Cancer 1994; **70**: 973-979.

Muir CS, Fraumeni JR, Doll R. The interpretation of time trends. In: Cancer Surveys volume 19/20: Trends in Cancer Incidence and Mortality. New York: Imperial Cancer Research Fund, 1994.

Muir CS, Storm HH, Polednak A. Brain and other nervous system tumours. In: Cancer Surveys volume 19/20: Trends in Cancer Incidence and Mortality. New York: Imperial Cancer Research Fund, 1994.

1995

Brewster D. Improving the quality of cancer registration data. J R Soc Med 1995; **88**: 268-71.

Brewster D, Muir CS, Crichton J. Registration of lung cancer in Scotland: an assessment of data accuracy based on review of medical records. Cancer Causes Control 1995; **6**: 303-10.

Brewster D, Muir CS, Crichton J. Registration of colorectal cancer in Scotland: an assessment of data accuracy based on review of medical records. Public Health 1995; **109**: 285-92.

Brewster D, Muir C, Crichton J. Registration of non-melanoma skin cancer in Scotland: how accurate are site and morphology codes? Clin Exp Dermatol 1995; **20**: 401-5.

Clarke K, Howard GCW, Elia MH, Hutcheon AW, Kaye SB, Windsor PM, Yosef HMA. Referral patterns within Scotland to specialist oncology centres for patients with testicular germ cell tumours. Br J Cancer 1995; **72**: 1300-1302.

Howard GCW, Clarke K, Elia MH, Hutcheon AW, Kaye SB, Windsor PM, Yosef HM, Sharp L. A Scottish national mortality study assessing cause of death, quality of and variation in management of patients with testicular non-seminomatous germ-cell tumours. Br J Cancer 1995; **72**: 1307-1311.

Howard GCW, Clarke K, Elia MH, Hutcheon AW, Kaye SB, Windsor PM, Yosef HMA. A Scottish national audit of current patterns of management for patients with testicular non-seminomatous germ-cell tumours. Br J Cancer 1995; **72**: 1303-1306.

Gould A, Muir CS, Sharp L. Prognosis and Survival in Prostate Cancer. In: Garraway M (editor). Epidemiology of Prostate Disease. Berlin Heidelberg: Springer-Verlag 1995; 214-24.

McKinney PA, Smith K, Findlay E. The Scottish Case Control Study of Childhood Leukaemia and Cancer: Methodology and Environmental Measures of Exposure. Health Bulletin 1995; **53:** 222-9.

McKinney PA, Sharp L, MacFarlane GJ, Muir CS. Oesophagus and gastric cancer in Scotland, 1960-90. Br J Cancer 1995; **71**: 411-415.

Muir CS. International patterns of cancer. In: Greenwald P, Kramer BS, Weed DL (eds). Science and Practice of Cancer Prevention and Control. New York: Marcel Dekker, 1995.

Percy C, Young JL, Muir CS, Ries L, Hankey BF, Sobin LH, Berg JW. Histology of cancer, Incidence and Prognosis: SEER Population-based data 1973-1987. Cancer (suppl) 1995; 75: 139-421.

1996

Bain M, Harvey JC, Muir CS. Cancer in Older Persons in Scotland. Health Bulletin 1996; **54**: 375-89.

Brewster D, Everington D, Harkness E, Gould A, Warner J, Dewar JA, Arrundale J. Incidence of and mortality from breast cancer since the introduction of screening (letter). Br Med J 1996; **312**: 639-640.

Brewster D, Crichton J, Harvey JC, Dawson G, Nairn ER. Benefits and limitations of pathology databases to cancer registries. J Clin Pathol 1996; **49**: 947-949.

Carnon A, Hole D, Gillis CR, Brewster D. Incidence of and mortality from breast cancer since the introduction of screening (letter). Br Med J 1996; **312**: 640.

MacFarlane GJ, Sharp L, Porter S, Franceschi S. Trends in survival from cancers of the oral cavity and pharynx in Scotland: a clue as to why the disease is becoming more common? Br J Cancer 1996; **73**: 805-808.

Muir CS, Harvey JC. Cancer of the Stomach (Review). GI Cancer 1996; **1**: 213-25.

Sharp L, Black RJ, Muir CS, Gemmell I, Finlayson AR, Harkness EF. Will the Scottish Cancer Target for the year 2000 be met? The use of cancer registration and death records to predict future cancer incidence and mortality in Scotland. Br J Cancer 1996; **73**: 1115-1121.

Sharp L, Black RJ, Harkness EF, McKinney PA. Incidence of childhood leukaemia and non-Hodgkin's lymphoma in the vicinity of nuclear sites in Scotland, 1968-93. Occ Environ Med 1996; **53**: 823-31.

1997

Bain MRS, Chalmers JWT, Brewster DH. Routinely collected data in national and regional databases – and under-used resource. J Public Health Med 1997; **19:** 413-418.

Bain M, Harvey JC, Muir CS. Epidemiology Research in Ageing: Perspectives and Limitations. in: Balducci L (ed) Comprehensive Geriatric Oncology (in Press).

Brewster D, Crichton J, Harvey JC, Dawson G. Completeness of case ascertainment in a Scottish Regional Cancer Registry for the year 1992. Public Health 1997; **111**: 339-343.

Crosher R, McIlroy R. Multiple primary malignancies in patients with oral cancer in Scotland. Br J Oral Maxillofac Surg (in press).

Muir CS, Harvey JC. Cancer of the stomach: overview. In: Sugimura T, Sasako M (editors). Gastric Cancer. Oxford: Oxford University Press, 1997.

Thames Cancer Registry

1994

Basnett I, Pollock AM, Gill M. Collecting data on cancer. Br Med J 1994; **308**: 791.

Bell CMJ, Chouillet AM. Management of breast cancer. (Letter). Br Med J 1994; **308**: 1508.

Bosch FX, Coleman MP. Descriptive epidemiology and human cancer. In: Love RR, ed. Manual of clinical oncology. Berlin: Springer, 1994; **35-55.**

Chouillet AM, Bell CMJ, Hiscox JG. Management of breast cancer in south-east England. Br Med J 1994; **308**: 168-171.

Coleman MP, Estève J. Trends in cancer incidence and mortality in the United Kingdom. In: OPCS, ed. Cancer statistics: registrations of cancer diagnosed in 1989, in England and Wales. Series MB1 no22 London: HMSO, 1994; 8-12**.**

EUROGAST Study Group. The epidemiology of low serum pepsinogen A levels and an international association with gastric cancer rates. Gastroenterology 1994; **107**: 1335-1344.

EUROGAST Study Group. O6-methylguanine in blood leucocyte DNA: an association with the geographic prevalence of gastric cancer and with low levels of serum pepsinogen A, a marker of severe chronic atrophic gastritis. Carcinogenesis 1994; **15**:1815-1820.

Horwich A, Bell CMJ. Mortality and cancer incidence following radiotherapy for seminoma of the testis. Radiother Oncol 1994; **30**: 193-198.

Lutz J-M, Coleman MP. Trends in primary cerebral lymphoma. Br J Cancer 1994; **70**: 716-718.

Mamelle N, Lacour A, Anes A, et al. Les expériences de dépistage de masse du cancer du sein par mammographie en France. Un protocole commun d'évaluation. Rev Epidémiol Santé Publ 1994; **42**: 34-49.

Pollock AM, Vickers N. The impact on colorectal cancer survival of cases registered by 'death certificate only': implications for national survival rates. Br J Cancer 1994; **70**: 1229-1231.

Pollock AM. The future of cancer registries. Br Med J 1994; **309**: 821-822.

Warnakulasuriya KAAS, Acworth P, Bell CMJ, Johnson NW. Incompleteness of oral cancer registration in South East England, 1971-1987. Br J Cancer 1994; **70**: 736-738.

1995

Coleman MP. Epidemiology of cancer. In: Horwich A, ed. Oncology - a multidisciplinary textbook. London: Chapman & Hall, 1995; **1-12.**

Ford D, Easton DF, Peto J. Estimates of the gene frequency of BRCA1 and its contribution to breast and ovarian cancer incidence. Am J Human Genetics 1995; **57**: 1457-1462.

Kaldor JM, Day NE, Kittelmann B, et al. Bladder tumours following chemotherapy and radiotherapy for ovarian cancer: a case-control study. Int J Cancer 1995; **63**: 1-6.

Pollock AM, Vickers N. The reliability of Thames Cancer Registry data on 673 cases of colorectal cancer: the effect of the registration process. Qual Health Care 1995; **4**: 184-189.

Pollock AM, Vickers N. Why are a quarter of all cancer deaths in south-east England registered by death certificate only? Factors related to death certificate only registrations in the Thames Cancer Registry between 1987 and 1989. Br J Cancer 1995; **71**: 637-641.

Pollock AM, Benster R, Vickers N. Why did treatment rates for colorectal cancer in South East England fall between 1982 and 1988? The effect of case ascertainment and registration bias. J Pub Health Med 1995; **17**: 419-428.

Schrijvers CTM, Mackenbach JP, Lutz J-M, Quinn MJ, Coleman MP. Deprivation, stage at diagnosis and cancer survival. Int J Cancer 1995; **63**: 324-329.

Schrijvers CTM, Mackenbach JP, Lutz J-M, Quinn MJ, Coleman MP. Deprivation and survival from breast cancer. Br J Cancer 1995; **72**: 738-743.

1996

Coleman MP, Lutz J-M. Tendances évolutives du cancer et prévision des besoins: vers une meilleure utilisation des registres du cancer. Rev Epidémiol Santé Publ 1996; **44**: S2-S6.

Garvican L, Littlejohn P. An evaluation of the prevalent round of the breast screening programme in South East Thames, 1988-1993: achievement of quality standards and population impact. J Med Screening 1996; **3**: 1-6.

Matthews G. Experts explore greater exploitation of cancer-registry data. Lancet 1996; **348**: 746.

Richards MA, Wolfe CDA, Tilling K, Barton J, Bourne HM, Gregory WM. Variations in the management and survival of women under 50 years with breast cancer in the South East Thames region. Br Med J 1996; **73**: 751-757.

1997

Ma M, Bell J, Cambell S, Basnett I, Pollock A, Taylor I. Breast cancer management: is volume related to quality? Br J Cancer 1997; **75**: 1652-1659.

UKACR and multi-registry studies

1994

Davies T, Williams EMI (eds) The Cancer Registry Handbook. UKACR, London, 1994.

Pheby DFH, Etherington DJ. Improving the comparability of cancer registry treatment data and proposals for a new national minimum dataset. J Pub Health Med 1994; **16**: 331-340.

1995

Bell CMJ, Lawrence G, Pheby DFH, Smith J, Coleman MP. The role of cancer registries. Clin Oncol 1995; **7**: 143-144.

Berrino F, Estève J, Coleman MP. Basic issues in estimating and comparing the survival of cancer patients. In: Berrino F, Sant M, Verdecchia A, Capocaccia R, Hakulinen T, Estève J, eds. Survival of cancer patients in Europe: the EUROCARE study. Lyon: IARC, 1995; 1-14.

EUROCARE Working Group. Comparisons of colon cancer survival among European countries: the EUROCARE study. Int J Cancer 1995; **63**: 43-48.

Kaldor JM, Day NE, Kittleman B, Prior P et al. Bladder tumours following chemotherapy and radiotherapy for ovarian cancer; a case-control study. Int J Cancer 1995; **63**: 1-6.

Quinn MJ, Allen E, United Kingdom Association of Cancer Registrations. Changes in incidence of and mortality from breast cancer in England and Wales since introduction of screening. Br Med J 1995; **311**: 1391-1395.

Sant M, Capocaccia R, Verdecchia A, et al. Comparisons of colon cancer survival among European countries: The EUROCARE Study. Int J Cancer 1995; **63**: 43-48.

Wilson S, Bell CMJ, Black R, et al. Health care system, cancer registration and follow-up of cancer patients in the United Kingdom. In: Berrino F, Sant M, Verdecchia A, Capocaccia R, Hakulinen T, Estève J, eds. Survival of cancer patients in Europe: the EUROCARE study. Lyon: IARC, 1995; 71-74.

1996

Alexander FE, Wray N, Boyle P, Bring J, Coebergh JW, Draper G et al. Review of clustering of childhood leukaemia: a European study in progress. J Epid & Biostats 1996; **1:** 13-24.

Gatta G, Sant M, Coebergh J-W, Hakulinen T, EUROCARE Working Group. Substantial variation in therapy for colorectal cancer across Europe: EUROCARE analysis of cancer registry data for 1987. Eur J Cancer 1996; **32A**: 831-835.

Parkin DM, Clayton D, Black RJ, Stiller CA. et al. Chilhood leukaemia in Europe after Chernobyl: Five year follow-up. Br J Cancer 1996; **73**: 1006-1012.

5 Reports and information produced by registries

This chapter presents details of statistical reports produced over the period 1993-97 by nine registries or their collaborators which make substantial use of registry data. More than fifty reports and statistical fact-sheets comprise the registries' main outputs for the NHS in the areas of public health, commissioning and strategy development.

The innovative electronic reports developed by the Northern and Yorkshire Cancer Registry and Information Service provide rapid access to statistics. Their website address is http://cbl.leeds.ac.uk/~ycr/registry/ycrhome.htm. It includes their annual report and incorporates an interactive facility called Quickdata which gives access to statistics and graphics (Figures 18,19).

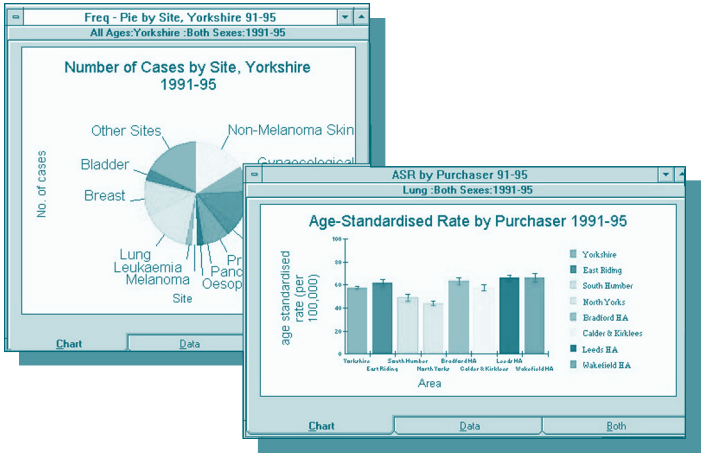


Fig 18 Pages from the Quickdata facility

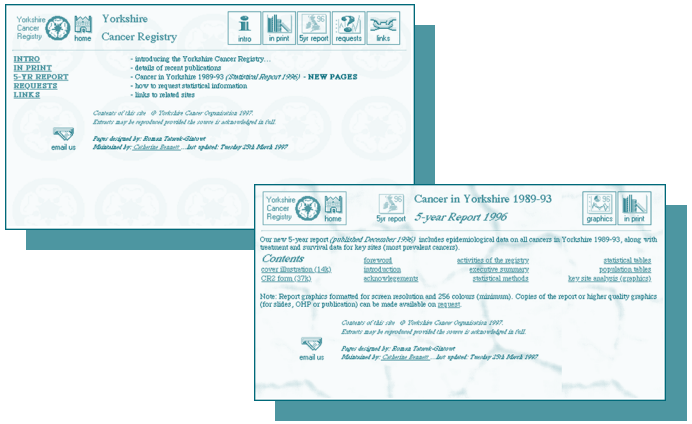


Fig 19 Pages from the Northern and Yorkshire Cancer Registry website

Merseyside and Cheshire Cancer Registry

Lung Cancer Bulletin: a framework for action (1993).

Breast Cancer Bulletin: stimulating the debate (1994).

Skin Cancer Bulletin: establishing the baseline (1994).

Northern & Yorkshire Cancer Registry and Information Service: reports

Breast Cancer in Yorkshire (1995) Cancer in Yorkshire, Special Report Series No. 3, (Forman D & Rider PL, eds) Yorkshire Cancer Organisation, Leeds.

Cancer in Yorkshire (1996) Cancer Registry Report, Cancer Statistics 1989-93, (Forman D & Rider PL, eds) Yorkshire Cancer Organisation, Leeds.

Cancer Treatment Policies, Delay in Referral and Effects on Survival: 1. Central Nervous System (1998) Northern and Yorkshire Cancer Registry and Information Service, Leeds.

Northern Ireland Cancer Registry: report

Cancer Deaths in Northern Ireland: an analysis of patterns and trends. O'Reilly D, Gavin A (eds) 1995.

North Western RCR – Centre for Cancer Epidemiology: reports

Threlfall A, Street A, Woodman CBJ et al. Economic evaluation of proposed changes to the breast screening programme, a report to the National Advisory Committee on Breast Cancer Screening. 1996. Centre for Cancer Epidemiology, West Pennine Health Authority, York Health Economic Consortium, Erasmus University, Rotterdam.

Prior P, Collins S and Woodman CBJ. Procedures for the investigation of cancer clusters: a discussion document. Centre for Cancer Epidemiology, Manchester, 1996.

Spencely M, Stevenson P, Woodman CBJ. et al. A report to the Manchester Intelligence group on the future configuration of services for head and neck cancer. Public Health Cancer Resource Centre, Centre for Cancer Epidemiology, Manchester, 1996.

Parry J. A report to Regional Advisory Committee on Oncology Services and the Public Health Cancer Resource Centre on the detection and management of solitary hepatic metastases after treatment of colorectal cancer. 1996.

Woodman CBJ. et al. Annual report to Purchasing Authorities. Centre for Cancer Epidemiology, Manchester, 1996.

Parry J. A report to purchasing authorities on workload statistics and referral patterns for patients with colorectal cancer in Greater Manchester and Lancashire. Centre for Cancer Epidemiology, Manchester, 1995.

Oxford Cancer Intelligence Unit: reports

Trends in Cancer Survival in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire. 1996.

Cervical Cancer in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire. 1997.

1994 Cancer Incidence in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire. 1997.

1995 Cancer Incidence and Survival in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire. 1998.

Scottish Cancer Intelligence Unit: reports

Information & Statistics Division. Scottish Health Statistics 1994. Edinburgh: ISD Publications, 1994.

Information & Statistics Division. Scottish Health Statistics 1995. Edinburgh: ISD Publications, 1995.

Information & Statistics Division. Scottish Health Statistics 1996. Edinburgh: ISD Publications, 1996.

Information & Statistics Division. Scottish Health Statistics 1997. Edinburgh: ISD Publications, 1997.

Black RJ, MacFarlane GJ, Maisonneuve P, Boyle P. Cancer Incidence and Mortality in Scotland 1960-89. Edinburgh: ISD Publications, 1995.

Brewster D, Crichton J, Muir CS. Accuracy of 1990 Cancer Registration Data in Scotland. Edinburgh: ISD Publications, 1994.

Clinical Outcome Indicators Working Group. Survival from selected cancers by Health Board. In: Clinical Outcome Indicators. pp 23-35. Edinburgh: The Scottish Office, 1996 (July).

Muir CS, McKinney PA. A strategy for cancer control in Scotland. Glasgow: Scottish Forum for Public Health Medicine, 1994.

Clinical Outcome Indicators Working Group. Survival from selected cancers by Health Board. In: Clinical Outcome Indicators. pp 11-33. Edinburgh: The Scottish Office, 1998 (March).

Scottish Breast Cancer Focus Group, Scottish Cancer Trials Breast Group, Scottish Cancer Therapy Network. Scottish Breast Cancer Audit 1987 & 1993. Edinburgh: SCTN, 1996.

South and West Cancer Intelligence Unit: reports

Trends in Cancer Survival in Wessex - 1973 to 1990. Wessex CIU, 1994.

Cancer in the South Western Region: Incidence and Survival in Key Sites. South Western CIU, 1994.

Cancer Statistics (Eastern Sector) and diskette 1993.

Cancer Statistics (Western Sector) and diskette 1993.

Colorectal Cancer in the South West 1995.

Cancer of the Female Breast in the South and West 1995.

Factsheets

Colorectal Cancer in the South and West. Factsheet no 1 1995.

Malignant Melanoma in the South and West. Factsheet no 2 1995.

Prostate Cancer in the South and West. Factsheet no 3 1995.

Breast Cancer in the South and West. Factsheet no 4 1996.

An Overview of Common Epidemiological Terms. Factsheet no 5 1996.

Lung Cancer in the South and West. Factsheet no 6 1997.

Cervical Cancer in the South and West. Factsheet no 7 1997.

Ovarian Cancer in the South and West. Factsheet no 8 1997.

Bladder Cancer in the South and West. Factsheet no 9 1997.

Improving care/clinical audit: head and neck cancer audit 1997.
Critical pathway analysis of referral, diagnosis and treatment patterns.
G Pearce and M Birchall, Southmead Hospital, Bristol.

Thames Cancer Registry: reports

General topics

Most common cancers in South East England, 1987-89: Incidence, treatment and survival. A report for the Cancer Services Review of the London Implementation Group. April 1993.

Benign and malignant neoplasms of bone, South East England, 1960-91: Incidence rates by morphological type. A report for Professor Robert Souhami, Clinical Oncology Department, University College London Medical School. October 1993.

Cancer in North Thames Region, 1991: Incidence, treatment and projections. A report for Dr Paul Cosford, Department of Public Health Medicine, North Thames RHA. May 1994.

Cancers of the lung and breast, South East England, 1975-91: Incidence, treatment and survival. A report commissioned by McKinsey & Company. April 1994.

Colorectal cancer in South East England: Incidence, prevalence, survival and treatment patterns for colorectal cancer patients resident in South East England. A report for Mr Ian Birch, Medical Liaison Officer, Zeneca Pharma. April 1995.

Cancer in South East England 1992. November 1995.

Cancer in South East England 1996. September 1997.

Reports for Public Health Departments giving Calman-Hine information on referral patterns

Commissioning cancer treatment services: the role of the regional cancer registry. 1994.

Cancer in Ealing, Hammersmith & Hounslow HA, 1992-93: Incidence, prevalence, survival and treatment patterns. 1994.

Cancer in East and West Kent HAs, 1991: Incidence, prevalence, survival and treatment patterns. 1995.

Cancers of the lung and breast, South East London, 1988-92: Incidence, prevalence, survival and treatment patterns. 1995.

Cancer in East and West Hertfordshire, 1992: Incidence, prevalence, survival and treatment. 1995.

Cancer in East London & The City, 1987-91: Incidence, prevalence, survival and treatment patterns. 1995.

Cancer in North Essex, 1992: Incidence, prevalence, survival and treatment patterns. 1995.

Cancer in Camden & Islington, 1991: Incidence, prevalence, survival and treatment. 1995.

Cancer in Bexley & Greenwich Health Authority, 1987-91: Incidence, survival and treatment patterns. 1995.

Cancer in New River Health Authority, 1992: Incidence, survival and treatment. 1995.

Cancer in Kingston & Richmond Health Authority, 1992: Incidence, survival and treatment patterns. 1996.

Cancer in Hillingdon Health Authority, 1992: Incidence, survival and treatment. 1996.

Cancer in South Essex Health Authority, 1992: Incidence, survival and treatment patterns. 1996.

Cancer in Barking & Havering Health Authority, 1992: Incidence, prevalence, survival and treatment patterns. 1996.

Cancer in Camden & Islington Health Authority, 1992: Incidence, prevalence, survival and treatment patterns. 1996.

Review of cancer treatment and referral patterns in South Thames: Treatment and referral patterns for cancer patients diagnosed in 1992 and resident in the South Thames area at the time of their diagnosis. 1996.

Cancer in North & South Bedfordshire, 1992: Incidence, prevalence, survival and treatment patterns. 1996.

Cancer in Kensington & Chelsea and Westminster, 1992: Incidence, prevalence, survival and treatment patterns. 1996.

Office for National Statistics, England and Wales: reports

Annual reports

Cancer statistics – registrations, England and Wales, 1987. Series MB1 no.20 OPCS. HMSO, London. 1993.

Cancer statistics – registrations, England and Wales, 1988. Series MB1 no.21 OPCS. HMSO, London. 1994.

Cancer statistics – registrations, England and Wales, 1989. Series MB1 no.22 OPCS. HMSO, London. 1994.

Cancer statistics – registrations, England and Wales, 1990. Series MB1 no.23 ONS. The Stationery Office, London. 1997.

Cancer statistics – registrations, England and Wales, 1991. Series MB1 no.24 ONS. The Stationery Office, London. 1997.

Monitors

Registrations of cancer diagnosed in 1990, England and Wales. Monitor MB1 95/1. OPCS, London. 1995.

Registrations of cancer diagnosed in 1991, England and Wales. Monitor MB1 96/1. ONS, London. 1996.

Incidence of and mortality from cancers of the lung, skin, breast and cervix - England. Monitor MB1 96/2. ONS, London 1996.

Registrations of cancer diagnosed in 1992, England and Wales, Monitor MB1 97/1. ONS, London. 1997.

6 The European dimension

Contributed by Dr.Max Parkin, Chief of the Unit of Descriptive Epidemiology, international agency for research on Cancer (IARC)

6.1 The European Network of Cancer Registries (ENCR)

Within the European Union, cancer control activities are promoted through the Europe Against Cancer programme of Directorate General V (Employment, Industrial Relations and Social Affairs). In 1990, Europe Against Cancer recognised the key role of cancer registries in planning and monitoring cancer control by supporting the establishment of a European Network of Cancer Registries (ENCR). The objectives of the ENCR are:

- to improve the quality, comparability and availability of cancer incidence data
- to create a solid basis for monitoring cancer incidence and mortality in the European Union
- to provide regular information on the burden of cancer in Europe
- to promote the use of cancer registry data for research and planning.

The ENCR has promoted a wide variety of activities within this framework, including educational activities such as a fellowships programme and training courses. A course on survival analysis was held in 1996. Other important areas have been standardising the technical aspects of registry work – for example by promoting uniform definitions and methods,[41,42] and disseminating information on cancer in Europe[39,43] In the latter context, the EUROCIM package is sent free to all participating registries, providing them with a powerful computer package for analysis and presentation of their own data, and that of other European registries for comparison purposes. The EUCAN90 software provides national level comparative statistics on incidence, mortality and prevalence of cancer; it is supplied as a computer diskette, and is now available on the Internet. www-dep.iarc.fr

Fig 20 Example graph from the EUCAN90 software

UK registries have played an active role in many ENCR activities, for example by hosting the ENCR course on cancer registration (South West CIU) in 1997, and chairing working groups on data definitions. A member of the steering committee of the ENCR is nominated by the UK Association of Cancer Registries.

6.2 Uncovering the causes of cancer

IARC utilises cancer registry data from Europe and other continents of the world in its programme to identify the causes of cancer and study the effectiveness of primary prevention programmes. For many years, IARC has supported the development of population-based cancer registration in all continents of the world[41,44-48], and made available comparable international cancer statistics. The seven volumes in the Cancer Incidence in Five Continents series[1,49,50] describe cancer incidence across the world since the 1950s. Time trends analyses[43] have detected increases in the incidence of testis cancer, adenocarcinoma of oesophagus, adenocarcinoma of cervix – indicating exposure to new risk factors.[8,43]

Registry data are correlated with data on exposure to different agents in the same geographic area, or over time, as a means of suggesting possible carcinogens. Examples are the correlations between gastric cancer and antibody to Helicobacter pylori in different regions in Europe (the Eurogast study)[51], or between acute myeloid leukaemia and environmental exposure to radon.[52]

Evidence from epidemiological case-control and cohort studies is reviewed in the IARC Monographs programme on carcinogenicity.[10] Such studies are generally accepted as providing the most powerful evidence for causality. Cancer registries are very frequently used to determine the outcome in prospective cohort studies. In this role, they have several advantages over the alternative mortality records. First, the quality of the information is higher: many deaths certified as 'cancer' prove not to be so, and there are mistakes in allocating the correct site. Secondly, the registry has more information on cancer cases (including details of histology and extent of disease). Finally, death may be a rather rare outcome for many cancers, so counting only deaths is at best an inefficient way to evaluate risk. Cohorts of individuals may be established from routine data sources (for example, hospital discharges following vasectomy, or a particular drug treatment), from occupational records, or by interviewing large numbers of subjects.

6.3 Cancer control

Once programmes to prevent cancer have been introduced, it is important to evaluate how successful they are in reducing cancer incidence, and here cancer registries have an important role. The IARC Scientific Publication No 103[53] 'Evaluating Effectiveness of Primary Prevention of Cancer' summarised the many types of evaluation, including comparisons between geographic areas with and without prevention programmes, and time trend studies concentrating upon the birth cohorts expected to benefit to randomised controlled trials, such as the trial of vaccination against hepatitis B in the Gambia, West Africa, where a cancer registry is used to monitor risk in vaccinated and unvaccinated individuals.[54]

References

1. Expert Advisory Group on Cancer to the Chief Medical Officer of England and Wales. Consultative Document: A Policy Framework for Commissioning Cancer Services. London: Department of Health, 1995
2. Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J (eds). Cancer Incidence in Five Continents Volume VII. Lyon: IARC, 1997: Scientific Publications No 143
3. Davies T, Williams L (eds). Cancer Registry Handbook: a guide to the use of cancer registries. London: United Kingdom Association of Cancer Registries, 1994
4. Winter H, Cheng KK, Cummins C, et al. Cancer incidence in the Asian population of England 1990-1992. Br J Cancer (in press) 1998
5. Office for National Statistics. Cancer statistics: registrations of cancer diagnosed in 1990, England and Wales. MB1 Series No 23. London: HMSO, 1997
6. Kemp I, Boyle PJ, Smans M, Muir CS (eds). Atlas of Cancer Incidence in Scotland. Lyon: IARC, 1985: Scientific Publications No 72
7. Kinlen LJ. Epidemiological evidence for an infective basis in childhood leukaemia. Br J Cancer 1995; **71:** 1-5
8. Stiller CA, Boyle PJ. Effect of population mixing and socio-economic status in England and Wales, 1979-85, on lymphoblastic leukeamia in children. Br Med J 1996; **313**: 1297-1300
9. Vizcaino AP, Moreno V, Bosch FX, Munoz N, Barros-Dios XM, Parkin M. International trends in the incidence of cervical cancer: adenocarcinoma and adenosquamous cell carcimomas. Int J Cancer 1998; **75**: 536-545
10. Stockton D, Cooper P, Lonsdale RN. Changing incidence of invasive adenocarcinoma of the uterine cervix in East Anglia. J Med Screening 1997; **4:** 40-43
11. International Agency for Research on Cancer. IARC Monographs on the Evaluation of Carcinogenic Risk to Humans. Lyon: IARC, 1998: Monographs on Cancer Risks published 1972-1998
12. Doll R, Peto R. The causes of cancer. J Natl Cancer Inst 1981; **66:** 1191-1308
13. Kaldor JM, Day NE, Kittelmann B, et al. Bladder tumours following chemotherapy and radiotherapy for ovarian cancer: a case-control study. Int J Cancer 1995; **63:** 1-6
14. Greenberg M. Ad hoc occupational mortality studies. In: Drever F, ed. Occupational Health: Decennial supplement. London: HMSO, 1995
15. Roman R, Carpenter L. Cancer incidence in England, 1981-87. In: Drever F, ed. Occupational Health: Decennial supplement. London: HMSO, 1995
16. Mersey Regional Cancer Registry. Lung Cancer Bulletin: a framework for action. Liverpool: Mersey Regional Cancer Registry, 1993
17. Quinn MJ, Allen E. Changes in incidence of and mortality from breast cancer in England and Wales since the introduction of screening. Br Med J 1995; **311:** 1391-1395
18. Herbert A, Breen C, Bryant TN, et al. Invasive cervical cancer in Southampton and South West Hampshire: effect of introducing a comprehensive screening programme. J Med Screening 1996; **3:** 23-28
19. Faux A, Richardson D, Lawrence GM, Wheaton M, Wallis M. Interval cancers in the NHS Breast Screening Programme: does the current definition exclude too many? J Med Screening 1997; **4:** 169-173
20. Woodman CBJ, Threlfall AG, Boggis CRM, Prior P. Is the three year breast screeing interval too long? Occurrence of interval cancers in the NHS screeing programme's north western region. Br Med J 1995; **310:** 224-226

21. Garvican L, Littlejohns P. An evaluation of the prevalent round of the breast screening programme in South East Thames, 1988-93: achievement of quality standards and population impact. J Med Screening 1996; **3:** 1-6
22. Ma M, Bell J, Campbell S, et al. Breast Cancer Management: Is volume related to quality? Br J Cancer 1997; **75:** 1652-1659
23. Selby P, Gillis C, Haward R. Benefits from specialised cancer care. Lancet 1996; **348:** 313-318
24. Gillis CR, Hole DJ, Still RM, Davis J, Kaye SB. Medical audit, cancer registration, and survival in ovarian cancer. Lancet 1991; **337:** 611-612
25. Junor EJ, Hole DJ, Gillis CR. Management of ovarian cancer: referral to a multidisciplinary team matters. Br J Cancer 1994; **70:** 363-370
26. Kehoe S, Powell J, Wilson S, Woodman C. The influence of the operating surgeon's specialisation on patient survival in ovarian carcinoma. Br J Cancer 1994; **70:** 1014-1017
27. McArdle CS, Hole D. An analysis of outcome following gastric cancer surgery. Gastrointestinal Cancer 1996; **1:** 177-182
28. McArdle CS, Hole D. Impact of variability among surgeons on postoperative morbidity and mortality and ultimate survival. BR MED J 1991; **302:** 1501-1505
29. Hakama M, Karajalainen S, Hakulinen T. Outcome based equity in the treatment of colon cancer patients in Finland. Int J Technol Assess Health Care 1989; 619-630
30. Kingston R, Walsh S, Jeacock J. Colorectal surgeons in district general hospitals produce similar survival outcomes to their teaching hospital colleagues: Review of 5 year survivals in Manchester. Journal of the Royal College of Surgeons, Edinburgh 1992; **37:** 235-237
31. Gatta G, Sant M, Coebergh J-W, Hakulinen T, EUROCARE Working Group. Substantial variation in therapy for colorectal cancer across Europe: EUROCARE analysis of cancer registry data for 1987. Eur J Cancer 1996; **32A:** 831-835
32. Sainsbury JRC, Rider L, Smith A, McAdam WFA. Does it matter where you live? Treatment variation for breast cancer in Yorkshire. British Journal of Cancer 1995; **71:** 1275-1278
33. Richards MA, Wolfe CDA, Tilling K, Barton J, Bourne HM, Gregory WM. Variations in the management and survival of women under 50 years with breast cancer in the South East Thames region. Br J Cancer 1996; **73:** 751-757
34. Basnett I, Gill M, Tobias JS. Variations in breast cancer management between a teaching and a non-teaching district. Eur J Cancer 1992; **28A:** 1945-1950
35. Gillis C.R, Hole D.J. Survival ourcome of care by specialist surgeons in breast cancer: a study of 3786 patients in the west of Scotland. Br Med J 1996; **312:** 145-148
36. Davies T and Stockton D. Report of cancer incidence and prevalence projections for the Cancer Relief Macmillan Fund. Cambridge: Dept of Community Medicine, Cambridge University, 1997
37. Thames Cancer Registry. Cancer in South East England 1992. London: Thames Cancer Registry, 1995
38. Berrino F, Sant M, Verdecchia A, et al. Survival of Cancer Patients in Europe. The EUROCARE Study. Lyon: IARC, 1995: Scientific Publications No 132
39. Carnon AG, Ssemwogerere A, Lamont DW, et al. Relation between socioeconomic deprivation and pathological prognostic factors in women with breast cancer. Br Med J 1994; **309:** 1054-1057

40. Stiller CA. Aetiology and Epidemiology. In: Pinkerton C.R, Plowman P.N, eds.Paediatric Oncology:Clinical practice and controversies. London: Chapman & Hall, 1998; 2nd edn
41. Parkin DM, Chen VW, Ferlay J, et al. Comparability and Quality Control in Cancer Registration. Lyon: IARC, **1994:** Technical Reports No 19
42. Storm H, Clemmensen I, Black N (eds). Survey of Cancer registries in the European Union. Lyon: IARC, **1998:** Technical Reports No 28
43. Coleman M, Esteve J, Damiecki P, Arslan A, Renard H (eds). Trends in Cancer Incidence and Mortality. Lyon: IARC, **1993:** Scientific Publications No 121
44. MacLennan R, Muir CS, Steiniz R, Winkler A (eds). Cancer Registration Techniques. Lyon: IARC, 1978: Scientific Publications No 21
45. Parkin DM, Wagner G, Muir CS (eds). The Role of the Registry in Cancer Control. Lyon: IARC, 1985: Scientific Publications No 66
46. Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG (eds). Cancer Registration: Principles and Methods. Scientific Publications No 95, Lyon; IARC,1991
47. Esteban D, Whelan SL, Laudico A and Parkin DM. Manual for Cancer Registry Personnel. Lyon: IARC, 1995: Technical Reports No 10
48. Black N, Simonato L and Storm HH. Automated Data Collection in Cancer Registration. Lyon: IARC, 1998: Technical Reports No 32
49. Muir CS, Waterhouse J, Mack T, Powell J, Whelan SL (eds). Cancer Incidence in Five Continents, Volume V. Lyon: IARC, 1987: Scientific Publications No 88
50. Parkin DM, Muir CS, Whelan SL, et al. Cancer Incidence in Five Continents,Volume VI. Lyon: IARC, 1992: Scientific Publications No 120
51. Forman D, Newell D, Webb P, et al. An international association between Helicobacter pylori infection and gastric cancer. Lancet 1993; **341:** 1360-1362
52. Henshaw DL, Eatough JP, Richardson RB. Radon as a causative factor in induction of myeloid leukaemia and other cancers. Lancet 1990; **335:** 1008-1012
53. Hakama M, Beral V, Cullen JW, Parkin M (eds). Evaluating Effectiveness of Primary Prevention of Cancer. Lyon: IARC, 1990: Scientific Publications No 103
54. Hall AJ, Inskip HM, Loik F, et al. The Gambia Hepatitis Intervention Study. Cancer Res 1987; **47:** 5782-5787

Abbreviations

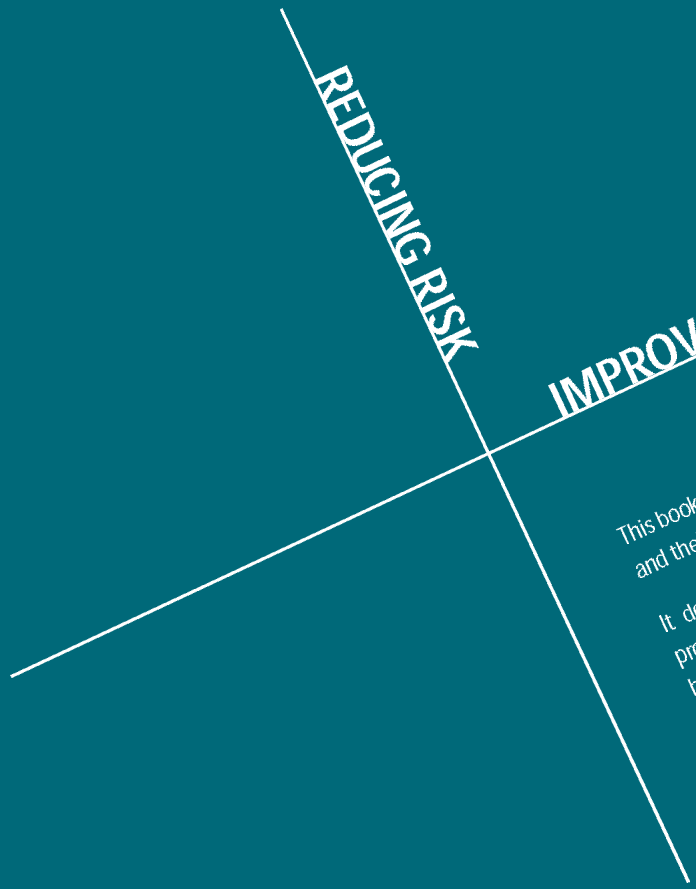
ACCR	Advisory Committee on Cancer Registration
ALL	Acute Lymphoblastic Leukaemia
ENCR	European Network of Cancer Registries
GIS	Geographical Information System
GRO	General Register Office
HES	Hospital Episode Statistics
HIV	Human Immunodeficiency Virus
HON	Health of the Nation
HSE	Health and Safety Executive
IARC	International Agency for Research on Cancer
ISD	Information and Statistics Division of the Common Services Agency for the NHS in Scotland
MRC	Medical Research Council
NHS	National Health Service
NHSCR	National Health Service Central Register
NHS NET	NHS Network for electronic dataflows within the NHS
NHS R&D	NHS Research and Development directorate
ONS	Office for National Statistics
QA	Quality Assurance
RSR	Relative Survival Rate
SAHSU	Small Area Health Statistics Unit
UKACR	United Kingdom Association of Cancer Registries

The UKACR member registries

• East Anglia Cancer Registry	01223 330318
• Merseyside & Cheshire Cancer Registry	0151 7945690
• Northern Ireland Cancer Registry	01232 263136
• North Western Cancer Registry - Centre for Cancer Epidemiology	0161 4463575
• Northern & Yorkshire Cancer Registry and Information Service	0113 2924309
• Office for National Statistics (ONS)	0171 5335257
• Oxford Cancer Intelligence Unit	01865 226742
• Scottish Cancer Intelligence Unit	0131 5518562
• South & West Cancer Intelligence Unit	01962 863511
• Thames Cancer Registry	0171 3787688
• Trent Cancer Registry	0114 2265351
• Wales Cancer Intelligence and Surveillance Unit	01222 373500
• West Midlands Cancer Intelligence Unit	0121 6272025

Associate members

- Childhood Cancer Research Group
- CRC Paediatric and Familial Cancer Research Group
- National Cancer Registry, Eire
- Marie Curie Cancer Care, London



IMPROVING OUTCOME in cancer

This booklet explains the work of cancer registries and their contribution to cancer control.

It demonstrates what UK cancer registries can provide for the ultimate benefit of cancer patients, both to reduce risk and to improve outcomes.

It also demonstrates the value for money to the NHS provided by cancer registries.

Designed by Format Information Design Ltd 01603 762745