

**united kingdom association of cancer registries**  
edited by CMJ Bell

# Preface

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

It is intended for NHS managers and clinicians, civil servants at the Department of Health, politicians, and others with a special interest in cancer. It demonstrates what UK cancer registries can provide to reduce risk for the general population and to improve outcomes for cancer patients. The 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 of the UK. It also demonstrates 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.

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Chairman 1995-98, UK Association of Cancer Registries

## 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, and 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 report was provided by the UKACR.

A long, referenced version of this booklet is available from the UK Association of Cancer Registries.

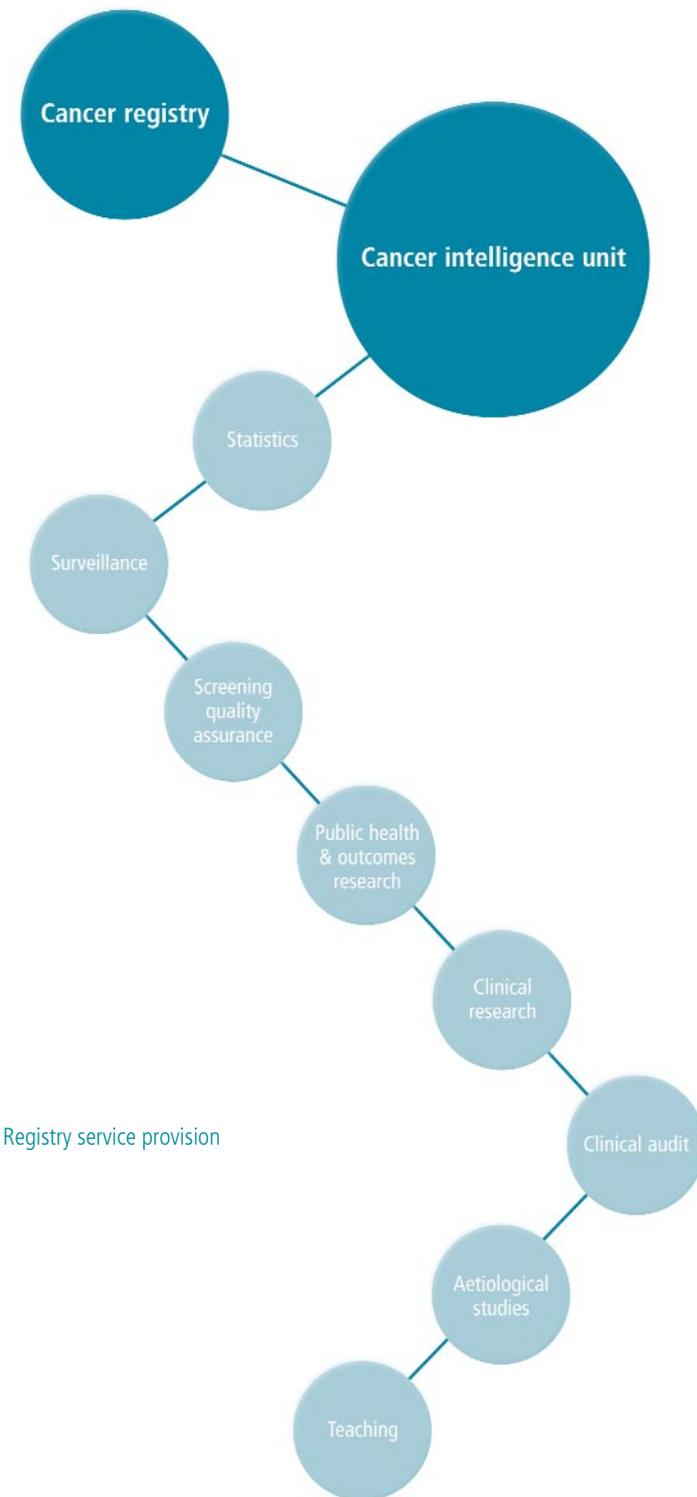


Fig 1 Registry service provision

# Cancer registration in the UK

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 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.

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 is 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 as described in this booklet.

Several of the registries also contribute to the published international cancer incidence statistics compiled by the International Agency for Research on Cancer (IARC) from a worldwide 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 data-sets.

## 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 NHS or private hospitals - including acute, long-stay, hospices and other hospitals - as well as data from general practitioners.

Comprehensive population-based coverage is essential for public health statistics, for 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, because of its relevance to political strategy.

## 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
- Clinicians in hospitals
- 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 (see Figure 1) are offered as a core function, free at the point of delivery.

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

- Published reports on cancer in the region (can include incidence, prevalence, survival)
- Data for evaluation of NHS screening programmes for breast and cervix cancer
- Data for specialist cancer registers such as the National Registry of Childhood Tumours in Oxford
- Bespoke 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 publication 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, clinical coders and medical undergraduates
- Advice on classification, coding and validation of cancer data for trusts and health authorities.
- Bespoke data collection services (haematology networks, screening QA and audit)
- Support for clinical trials
- Support for clinical audit

## Types of data available

The registries have databases spanning 30 or more years, typically covering cancers diagnosed 1960-98. These databases represent a priceless resource for epidemiological research.

For each registered tumour, the current data-set describes:

- the person:** age, sex, postcode of residence,
- the tumour:** site, histology, date of diagnosis, and the stage of disease for some sites
- 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 data sets. 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 or (Calman-Hine) re-organisation of cancer services.

The complexity of the analyses varies enormously; frequently initial descriptive analysis is followed up by bespoke analytical studies to investigate specific questions. Descriptive studies may examine incidence, mortality, prevalence and survival. Analytical studies examine questions generated by descriptive observations or laboratory studies.

## The European dimension

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 (the ENCR).

UK registries have played an active role in many ENCR activities, for example by hosting the ENCR course on cancer registration at South and West CIU in 1997, and chairing working groups on data definitions.

## 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 under £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.

## Confidentiality

The registry databases contain confidential information on millions of persons, compiled over several decades. The security and confidentiality arrangements are the prime responsibility of the directors of the registries. The principles and procedures are described in the UKACR handbook (UKACR, 1994).

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 will follow the European directive on confidentiality.

## Improving performance

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

# 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. Cancer registries have a long history of contributing to epidemiological research into causes of cancer and evaluating screening programmes.

## 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.

Comparisons of age-standardised incidence rates between countries have provided many important clues to the causes of cancer. These 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.

### Deprivation

Registries can group patients by deprivation score, assigned by linking post-code of residence to Census data. The West Midlands registry, for example, has shown that cancer risk can vary significantly according to deprivation score. In Merseyside risk varies according to lifestyle 'super profiles'.

### Ethnic origin

Ethnic origin has been collected as part of the national cancer registry minimum data-set since 1993, and in the NHS Contract Minimum Data-set 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.

### 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 such as testicular cancer and Hodgkins disease varies markedly between UK regions.

### Time-trends

Most registries in the UK have data spanning several decades, consistently recorded. Time-trends in incidence may suggest that the population is exposed to new risk factors.

## 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 - 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 are cigarette smoking and diet, followed by reproductive factors, occupational exposures and geophysical factors.

Cancer registries are 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

In order to facilitate research on childhood cancers, there is a National Registry of Childhood Tumours maintained and extensively used by the Childhood Cancer Research Group at Oxford.

#### Risks following cancer treatment

So many cancer patients now survive long-term that clinicians need to consider the long-term effects of the intensive regimes used to conquer the cancer. Registries provide the follow up needed for such studies.

#### Genetic risk

Cancer registries are a unique resource for genetic research. Registries can be used to systematically identify individuals or sub groups at high risk of cancer. They can also be used to monitor cancer incidence in high-risk groups in the population.

All the UK registries are also used by the regional genetic counselling services to trace and confirm cancer in relatives of patients being counselled.

#### HIV

HIV infection leads to an increased risk of cancer. 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.

## 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.

### National policy targets

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

### 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 3-5 years. The effects on incidence and outcome can be monitored using the regional registry.

### Breast screening

Interval cancers are used as a measure of the success (or failure) of the programme. There is concern that the three year screening interval is too long, and that uptake is low in the least affluent groups.

# Improving outcome

## Improving services

The Calman-Hine report in 1995 recommended the use of cancer registries to monitor the quality of cancer treatment and specialisation. As a result, over the past three to four years, the UK registries have been increasingly active in regionwide clinical audit projects.

These audits increase the level of collaboration between registries and clinical practice. They also provide Trusts and Health Authorities with comparable measures of workload, performance and outcome.

## Improving outcome

The Calman-Hine recommendations were based on the view that specialisation would improve outcomes. The majority of the evidence supporting that view 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.

Several 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. These studies showed that multidisciplinary therapy yields benefits. Benefits seem to depend more on the treatment than the type of hospital where treatment is delivered

Large variations between surgeons in outcome of gastric cancer were found in Scotland

Large variations between surgeons have been found in both the care and outcome of colorectal cancer patients. In Finland, it was estimated that management of patients in a specialist teaching hospital increased the chances

of survival by about 10-15%. A study by North Western registry has shown that a specialist surgeon can achieve similar results in a teaching hospital or a non-teaching hospital

Large variations in care and outcome were found for breast cancer patients in Yorkshire. Surgeons who had an annual caseload of more than 30 patients compared with those treating fewer than 10 patients, had significantly better results, with their patients having a 15% lower risk of death

Other population based studies on breast cancer in South East Thames, North East Thames, and Scotland, have provided further evidence of better outcome in specialist centres

The survival of children with leukaemia is better if they are in clinical trials or specialist centres.

## 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, but are important for commissioning services. In a recent forecast (East Anglian Cancer Registry) a substantial 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.

### 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.

### Measuring outcome

#### Survival

Registries record the date of death and can compute survival. The registries routinely receive prompt notification of deaths due to cancer, 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.

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.

Survival outcome is extremely important information for health commissioners and patient organisations, as well as the treating clinicians.

The EURO CARE study was a major international multi-registry collaboration, which showed large differences in outcome between European countries. Survival in the UK was worse than the European average for most common cancers, and supported the need for initiatives to improve outcome in the UK.

### 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. 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 the patient representative groups such as Cancer Relief Macmillan Fund, BACUP, Cancerlink, and the National Cancer Alliance.

### 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 efficacy of treatment may play a major role. 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.

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

# Research, reports and information outputs

## Research

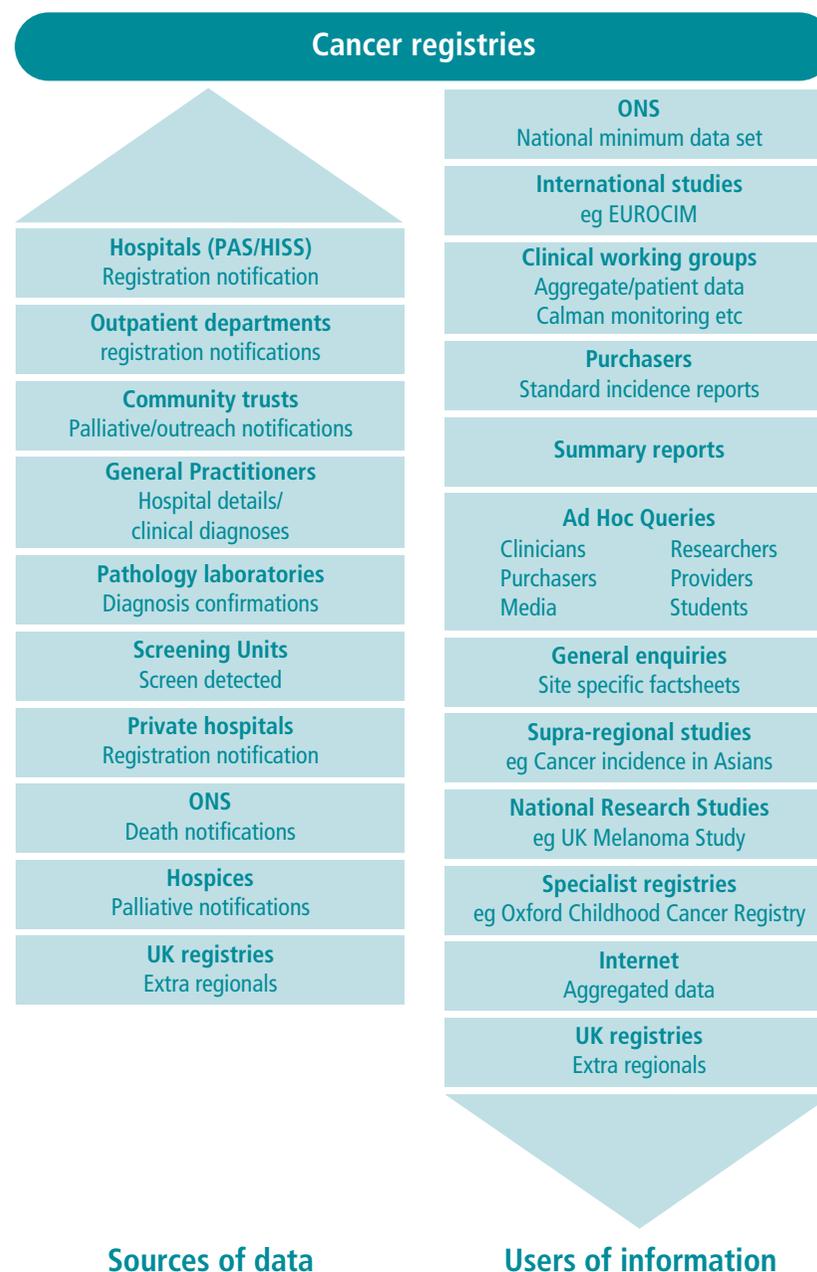
Papers published in peer-reviewed journals are an accepted measure of research activity. Registries represent a formidable resource for research. The output from the thirteen registries between 1994-97 exceeded 200 published papers. In addition, there are papers resulting from multi-registry national and international collaborations. (Details of these papers are published in the full version of this booklet.)

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 institutes of public health.

## Reports and information produced by registries

The statistical reports produced (listed in the full version of this booklet) make substantial use of registry data. More than fifty reports and statistical factsheets since 1993 comprise the registries' main outputs for NHS public health, commissioning and strategy development.

The innovative electronic reports developed by the Northern and Yorkshire Cancer registry 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.



# Glossary

**GRO**

General Register Office

**ONS**

Office for National Statistics, for England and Wales

**UKACR**

United Kingdom Association of Cancer Registries

## The UKACR member registries

East Anglia Cancer Registry

Merseyside & Cheshire Cancer Registry

Northern Ireland Cancer Registry

North Western Cancer Registry - Centre for Cancer Epidemiology

Northern & Yorkshire Cancer Registry and Information Service

Office for National Statistics (ONS)

Oxford Cancer Intelligence Unit

Scottish Cancer Intelligence Unit

South & West Cancer Intelligence Unit

Thames Cancer Registry

Trent Cancer Registry

Wales Cancer Intelligence and Surveillance unit

West Midlands Cancer Intelligence Unit

## Associate members

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**REDUCING RISK**

**IMPROVING OUTCOME**  
in cancer

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