

An Information Guide to the National Cancer Registry

Prepared in accordance with Section (15) of the Freedom of Information Act



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Introduction

Description

The National Cancer Registry was set up by the Department of Health & Children in 1991 to record information on all cancer cases occurring in the Republic of Ireland. The Registry is funded by the Department of Health.

The past thirty years have seen major advances in the fight against cancer, with both improvements in the effectiveness of treatment and reductions in the risk of developing some common cancers. Cancer research has been, and will continue to be fundamental to these advances. In Ireland, the National Cancer Registry is an important part of our fight against cancer.

Staff

Currently there are forty eight people employed by the Registry together with nine externally funded researchers. This includes twenty two Tumour Registration Officers based in hospitals throughout the country.

Budget

The Registry operates with a budget of just under €3m which comes from the Department of Health.

Area and Population

The registry collects cancer related data from all counties in the Republic of Ireland which has a population of over 4.4 million people.

Functions

The Registry was established in 1991 by the Minister for Health under The National Cancer Registry Board Establishment Order.

The National Cancer Registry Board was established by the Minister for Health in 1991, by Statutory Instrument. Its functions were laid down in its Establishment Order as follows:

1. to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland;
2. to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs;
3. to promote and facilitate the use of the data thus collected in approved research and in the planning and management of services;
4. to publish an annual report based on the activities of the Registry;
5. to furnish advice, information and assistance in relation to any aspect of such service to the Minister.

The current National Cancer Registry Board (August 6th 2011 - August 5th 2012) was appointed by the Minister for Health in August 2011. The Board members are:

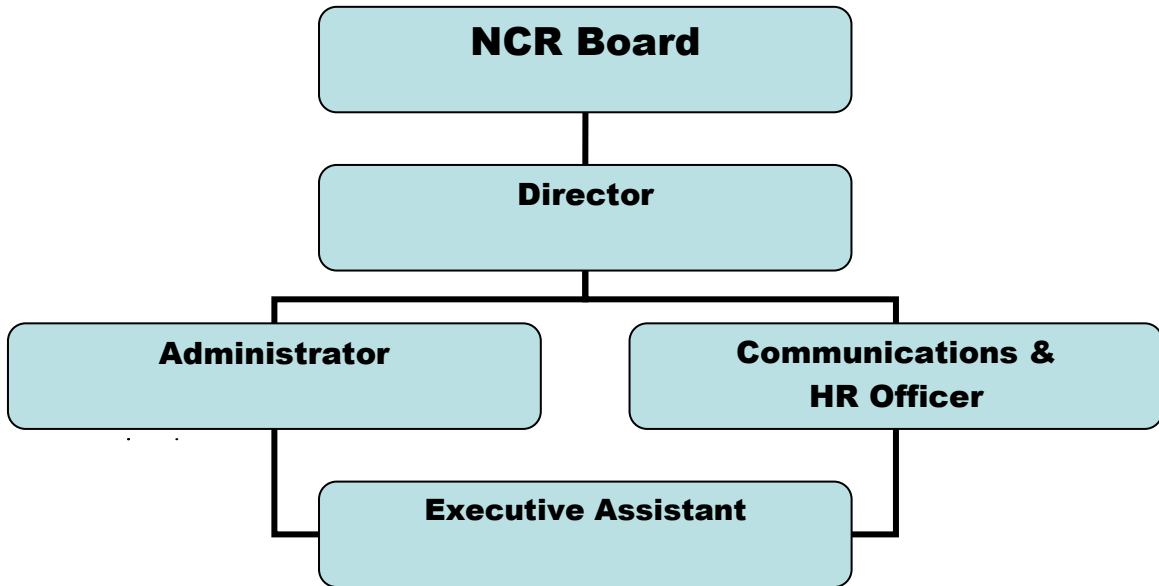
| National Cancer Registry Board | |
|---------------------------------------|-------------------------|
| Member | Nominated By |
| Mr Tony O'Brien (Chair) | Ministerial Appointment |
| Professor Donal Hollywood | Ministerial Appointment |
| Dr Anna Gavin | Ministerial Appointment |
| Ms Mary Jackson | Ministerial Appointment |
| Dr Deirdre Murray | Ministerial Appointment |
| Mr John McCormack | Ministerial Appointment |
| Professor Paul Redmond | Ministerial Appointment |

Mission Statement

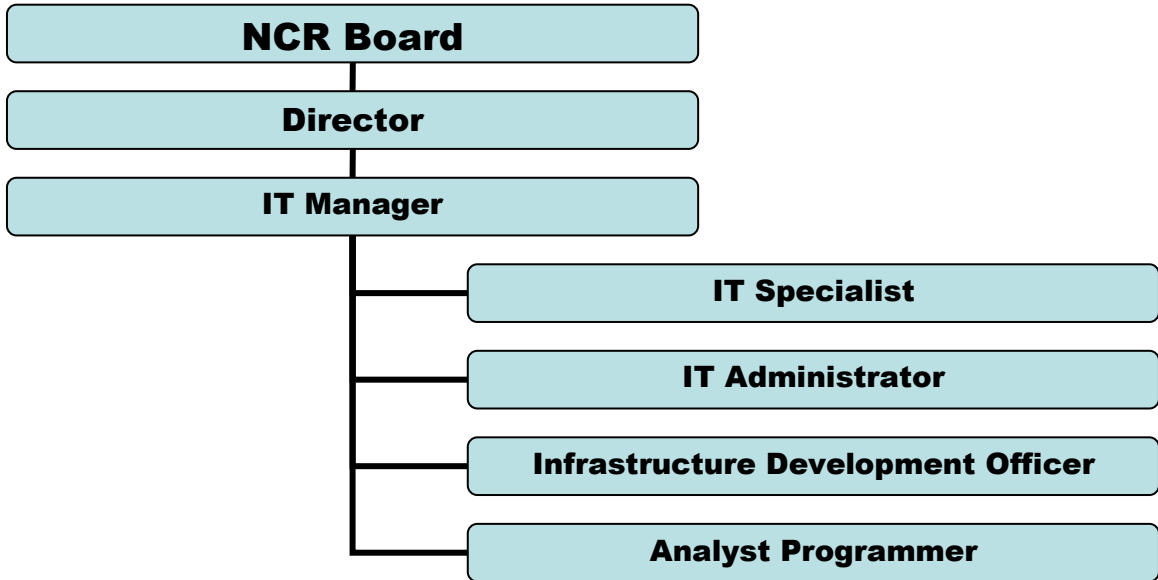
Mission Statement

The aim of the National Cancer Registry is to collect high quality information on cancer and to promote the use of this information in reducing cancer incidence and improving survival

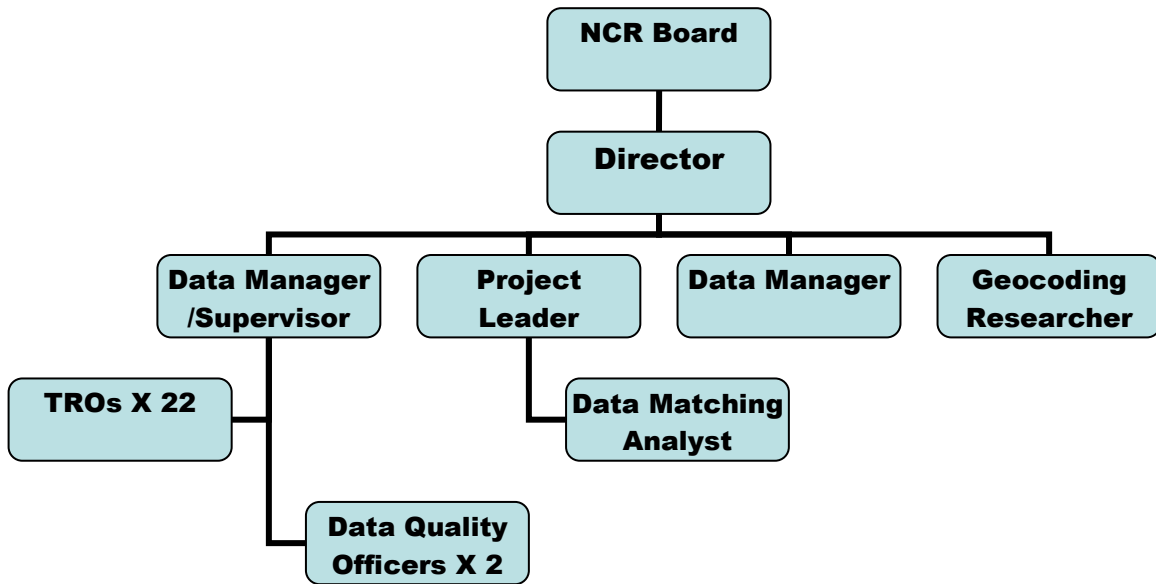
**National Cancer Registry
Administration Department**



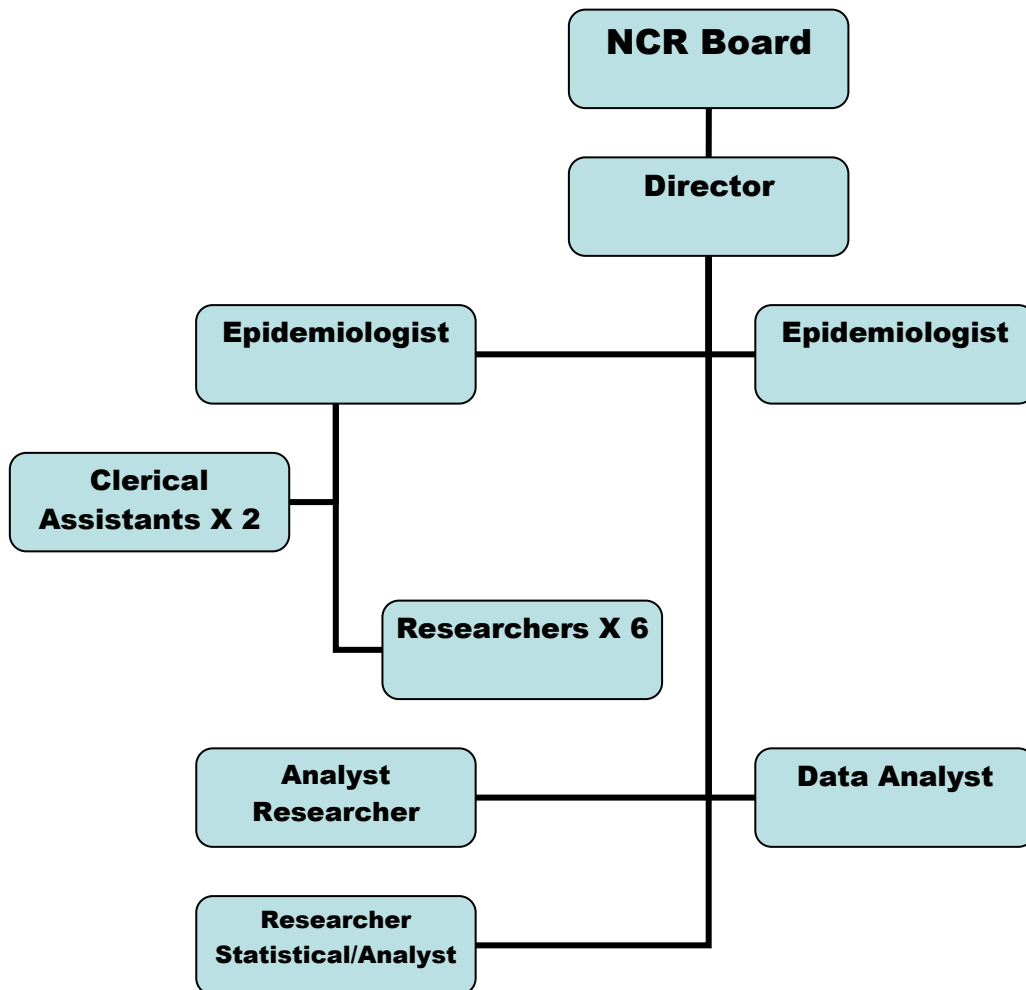
**National Cancer Registry
Information Technology Department**



**National Cancer Registry
Data Department**



**National Cancer Registry
Research Department**



Role of the National Cancer Registry

The Registry provides indicator and research data on cancer control, from prevention through screening, to treatments and outcomes as well as identifying socio-economic and geographical disparities in cancer related risk factors. This information is essential for effective targeting of cancer services.

Data collected and held by the National Cancer Registry is of importance to the following key client groups;

- a) The General Public and their representatives
- b) Health services planners and administrators
- c) Health professionals
- d) The epidemiology and cancer research communities

The Registry makes a significant contribution to health gain by providing an evidence base for the assessment of Irish cancer services by:

- ◆ Identifying current cancer risks to the Irish population
- ◆ Monitoring temporal and geographical trends in these risks
- ◆ Identifying populations at risk
- ◆ Providing data for researchers on cancer

Priority Objectives

The needs which have been identified by consultation with our client groups include;

- a) More timely information
- b) More detailed information on treatment and follow up
- c) Detailed targeted reports on subsets of the data e.g. for individual health boards or hospitals
- d) Extended patient dataset to include information on small area of residence and socio-economic status
- e) A wider range of international comparative data, especially on cancer outcomes

Registry Activity

The primary activity of the National Cancer Registry is the maintenance of a national database of all new cancers. Reporting to the Registry is voluntary, and data collection is mainly active. The only information received passively at present is through notifications returned by GPs. All other information is actively gathered by nurses who are trained in cancer registration methods. These nurses are called Tumour Registration Officers (TROs) and are based in hospitals throughout the country. Each is responsible for gathering data from a group of hospitals, and from other sources within a designated geographical area. Within their catchment areas, they liaise with hospital pathology and haematology laboratories, special clinics, hospital administrators and medical records staff, HIPE and casemix staff, and any other persons they consider to be a useful source of cancer registration data. They also maintain links with public health nurses, hospices and nursing homes in the community. Although HIPE (Hospital Inpatient Enquiry Scheme) data are pooled nationally, data acquisition from HIPE system is done locally, as patient names are not available on the HIPE data centrally, making it impossible to match registrations with HIPE records.

The Tumour Registration Officers enter this data onto laptop computers and send it electronically to the Registry headquarters in Cork where it undergoes quality control.

Cases are also identified through the death certification system, although these represent just 2% of all cases registered. The Registry has access through the CSO, to all death certificates issued since January 1994. Deaths due to cancers which are not already known to the Registry are followed up by enquiries to the relevant hospital or the patient's GP. Existing registrations are automatically updated with death certificate information.

In response to requests from users, and by comparison of our dataset with that of other registries, we have added a number of new data items to the system. All of these developments, while enhancing the value of the data, slow the process of registration and add to the amount of data to be processed and checked at the registry.

National Cancer Registry Dataset

The dataset below is current. Most, but not all, of the data below is available from 1/1/1994. The data is held at three levels: patient, tumour and treatment. "Treatment" can include any activity for which there is an ICD 9-CM code, including diagnosis and consultation. We attempt to record each hospital at which a patient is seen.

| Patient file | Tumour file | Treatment file |
|--|---|--|
| registration number | patient registration number | patient registration |
| surname | tumour sequence | tumour sequence |
| maiden name | source of notification (pathology, death certificate, GP etc. | treatment sequence number |
| other surname | method of presentation (symptoms/incidental/screening) | treatment code (ICD9 CM) |
| first name | GP code & GP referral date | treatment date |
| other first name | GP practice | hospital |
| address | | consultant |
| county | | medical record number |
| alternative address | | admission type (Daycase, Inpatient, Outpatient, Emergency) |
| health services numbers | incidence date | treatment intent (Primary, Diagnostic, Palliative, Recurrence, Metastasis) |
| smoking status (yes/no/ex-smoker/unknown) | age at diagnosis | site of treatment |
| date of birth | number of tumours (non melanoma skin cancer) | |
| sex | topography (ICD O 2) to 31/12/04 topography (ICD O 3) from 01/01/05 | |
| marital status | laterality | |
| occupational code (standard occupational classification) | morphology (ICD O 2) to 31/12/04 morphology (ICD O 3) from 01/01/05 | |
| whose occupation; indicates relationship to patient, ie own, spouse, parent, unknown | grade | |
| occupational status (unemployed, retired etc.) | | |
| alive or dead or unknown | tumour markers (PSA/ER/PR/HER) | |
| date of death | method of diagnosis (histology cytology/ bone marrow/ blood film/ clinical/radiology/ postmortem /other/ unknown) | |
| cause of death (ICD9 or ICD10, depends on when death occurred) (by linkage) | site for staging purposes | |
| | cT/cN/cM/pT/pN/pM | |
| | T N and M stage certainty factor (from UICC/AJCC) | |
| | residual disease code | |
| | site and date of metastases | |
| | pathology reference number | |
| | date of histology report | |
| | pathologist code | |
| | pathology lab | |
| | date of recurrence | |
| | ICD10 code | |

Other data can be added by linkage, for instance:

- | | |
|------------------------------------|--|
| a) ED code of residence | b) Comorbidity (from HIPE data) |
| c) Length of stay (from HIPE data) | d) Clinical details (from hospital clinical oncology IT systems) |

Ireland-Northern Ireland-National Cancer Institute Consortium

Cross Border Co-operation

The Ireland-Northern Ireland-National Cancer Institute Cancer Consortium was established in 1999 at the Stormont Parliament Buildings in Belfast, Northern Ireland. The ceremonial signing of the *Memorandum of Understanding* was chaired by former U.S. Senator George Mitchell.

The goal of the Consortium is to reduce the incidence of cancer in both parts of Ireland, which have amongst the highest rates of cancer in the western world. The Consortium is regarded as a major step towards enhancing relations between Ireland and Northern Ireland, bringing both parts of the island together in a common cause.

Goals

Major goals of the Consortium are to:

Enhance and coordinate the cancer registries of Ireland and Northern Ireland so that more can be learned about cancer incidence on the entire island. Conduct joint clinical research studies involving people from all three jurisdictions. Develop and sponsor formal training programmes for Irish and American medical, nursing, and scientific scholars. Implement the use of advanced information and technologies to enhance clinical research and facilitate education.

Joint programmes will help researchers understand more about cancer rates, trends, and outcomes on the entire island by identifying geographic and population differences in cancer patterns. Additionally, the combined cancer data can be linked to other information sources to study possible relationships between cancer incidence and environment, occupation, and lifestyle influences.

All-Ireland Cancer Statistics Reports

In May 2001, the Consortium announced the findings of the first All-Ireland Cancer Statistics report. This was a joint effort of the two registries to document cancer rates, trends, and outcomes on the entire island of Ireland. In September 2004, the consortium produced the second All-Ireland Cancer Statistics report followed in April 2009 by a third. These are the first three collaborative reports of the two cancer registries and the first jointly produced products to be delivered by the Consortium.

Concepts for future collaboration between the registries include reporting on cancer survival and patterns of care for the entire island.

Cancer Epidemiology

Three cancer fellows have concluded their postdoctoral study in cancer epidemiology at the National Cancer Institute in Maryland, USA. One is now employed as an epidemiologist at the National Cancer Registry in Cork and one is based in Northern Ireland. Both are now involved in research projects in Ireland. It is anticipated that they will help direct collaborative clinical research activity on the island of Ireland, which is a long-term strategy of the Consortium.

Cancer Prevention

Promoting prevention in the management of cancer is a long-term goal of the Consortium and, as a result, the Consortium encourages scholar exchange in the area of prevention.

How To Access Information Held By The National Cancer Registry

Routinely Available Information.

The National Cancer Registry currently makes a large volume of information available to the public in relation to its functions and activities. This can be found on its website at www.ncri.ie. A list of publications is available in Appendix (1) of this manual. These publications are available either in report form or on the registry website.

Such information will continue to be available informally without the need to use the FOI Act. This applies in particular to requests for general information broken down into broad categories such as age group, sex and county.

The FOI Act is designed to allow public access to information held by public bodies which is not routinely available through other sources. Access to information under the Act is subject to certain exemptions and involves specific procedures and time limits. This manual provides a guide to the structure of the National Cancer Registry, Ireland so as to help you access information under the Freedom of Information Act.

Applications under the Freedom Of Information Act, 1997

Under the FOI Act, anyone is entitled to apply for access to information not otherwise publicly available. Each person has a right to:

- access records held by the National Cancer Registry.
- correct personal information relating to oneself held by the National Cancer Registry where it is inaccurate, incomplete or misleading.
- access reasons for decisions made by the National Cancer Registry directly affecting oneself.

The following records come within the scope of the Act:

- all records held by the National Cancer Registry which were created after the 21st April 1998.
- Any record created before the 21st April 1998 if this record is necessary for understanding a record created after 21st April 1998.
- all personal information about the requester which is held by the National Cancer Registry, regardless of when the records were created.

Applications for information under the FOI Act should be submitted to:

Ms Geraldine Finn
FOI Officer
National Cancer Registry, Ireland
Building 6800
Cork Airport Business Park
Kinsale Road
Cork

Tel: 021-4548803
Fax: 021-4318016
Email g.finn@ncri.ie

Procedures for accessing information under the Freedom of Information Act, 1997

Applications should be made in writing and should indicate that the information is sought under the Freedom of Information Act, 1997. Requests sent by post should be sent to the following address:-

Ms Geraldine Finn
National Cancer Registry
Building 6800
Cork Airport Business Park
Kinsale Road
Cork

In preparing a request the following guidelines should be followed.

- State that the request is made under the Freedom of Information Act, 1997.
- Provide as much detail as possible to enable staff of the National Cancer Registry to identify the record.
- Provide full personal details including name, address and contact telephone number.
- State if the information is required in a particular form i.e. photocopy or computer disk.

How Freedom of Information Applications are Dealt with

The Freedom of Information Act, 1997 sets down strict time limits for processing requests.

- ◆ The National Cancer Registry is obliged to acknowledge your request within two weeks from the date of receipt.
- ◆ You will be given the name of the person dealing with your request.
- ◆ The National Cancer Registry is obliged to respond to your request within four weeks of receipt. It may be necessary to extend this period for up to four more weeks if:
 - a) Your request relates to a very large number of records, or a large number of requests for the same record(s) have been made.
 - b) If the period is extended, you will receive notice of this before the end of the initial four week period, and the reasons for the delay will be given.

If your request is granted:

- ◆ You will receive a letter stating that your request has been granted and the name of the person dealing with it.
- ◆ You will be given the time frame within which this request will be granted.
- ◆ You will be given details of any fees involved if applicable.

Rights of Review and Appeal

The Act sets out a series of exemptions to protect sensitive information where its disclosure may damage key interests of the State or of third parties. Where the National Cancer Registry invokes these provisions to withhold information, the decision may be appealed. Decisions in relation to deferral of access, charges, forms of access, etc. may also be the subject of appeal. Details of the appeal mechanisms are as follows:

Internal Review

You may seek internal review of the initial decision which will be carried out by an official at a higher level if:

- a) You are dissatisfied with the initial response received, i.e. refusal of information, form of access, charges, etc, or
- b) You have not received a reply within four weeks of your initial application.

This is deemed to be a refusal of your request and allows you to proceed to internal review.

Requests for internal review should be submitted in writing to:

Dr Harry Comber
Director
National Cancer Registry
Building 6800
Cork Airport Business Park
Kinsale Road
Cork

Tel 021-4548801
Fax 021-4318016
email h.comber@ncri.ie

These reviews should clearly state that they are **Freedom of Information** requests. They must be submitted within four weeks of the initial decision. The National Cancer Registry must complete the review within three weeks of receipt of internal review application. Internal review must normally be completed before an appeal may be made to the Information Commissioner.

Review by the Information Commissioner

If following completion of the internal review you still have been refused in part or total, you may seek independent review of the decision from the Information Commissioner. Also if you have not received a reply to your application for internal review within three weeks, this is deemed to be a refusal and you may appeal the matter to the Commissioner.

In general an application for review by the Commissioner must be made within 6 months of the notification of the decision by the public body.

Appeals must be made in writing to the Information Commissioner at the following address:

Office of the Information Commissioner
18 Lower Leeson Street
Dublin 2

Tel 01-6785222
Fax 01-6610570
email foi@ombudsman.irlgov.ie

LoCall 1890 223030

The Commissioner's decision can be appealed to the High Court on a point of law only.

Fees

Application fees

A standard application fee of **€15** must accompany an FOI request made under section 7 of the Act for a record or records **containing non-personal information**.

A reduced fee of **€10** applies if the person making such a request is covered by a medical card.

The following requests/applications are exempt from application fees:

- (a) A request under section 7 for a record or records containing only personal information related to the requester.
- (b) An application under section 17 (right of amendment of records relating to personal information).
- (c) An application under section 18 (right of person to information regarding acts of public bodies affecting the person).

Internal review fees

A standard application fee of **€75** must accompany an application for internal review under section 14 of the Act.

A reduced fee of **€25** applies if the person bringing the application is a medical card holder or a dependant of a medical card holder.

The following internal review applications are exempt:

- (a) An application in relation to a decision concerning records containing only personal information related to the applicant.
- (b) An application in relation to a decision under section 17 (right of amendment of records relating to personal information).
- (c) An application in relation to a decision under section 18 (right of person to information regarding acts of public bodies affecting the person).
- (d) An application in relation to a decision to charge a fee or deposit, or a fee or deposit of a particular amount.
- (e) An appeal of a decision which is deemed to be refused because the original request was not replied to within the required time limits.

Review by Information Commissioner

A standard application fee of **€150** must accompany applications to the Information Commissioner for review of decisions made by public bodies under section 34 of the Act.

A reduced fee of **€50** applies if

- (a) the person bringing the application is a medical card holder or a dependant of a medical card holder or
- (b) the person is specified in section 29(2) i.e. a third party with the right to apply directly to the Information Commissioner where a public body decides to release their information on public interest grounds.

The following applications to the Information Commissioner do not require an application fee:

- (a) An application concerning records containing only personal information related to the applicant.
- (b) An application in relation to a decision under section 17 (right of amendment of records relating to personal information).

- (c) An application in relation to a decision under section 18 (right of person to information regarding acts of public bodies affecting the person).
- (d) An application in relation to a decision to charge a fee or deposit exceeding €25.00 under section 47 in respect of search and retrieval and photocopying of records (decisions in relation to the charging of fees or deposits for search and retrieval and/or photocopying of less than €25 are not subject to review by the Information Commissioner).
- (d) An application in relation to a decision to charge a fee under section 47(6A), or a fee of a particular amount under section 47(6A), on the grounds that the records concerned do not contain only personal information related to the requester or the requester is not a medical card holder or a dependant of a medical card holder.
- (e) An appeal of an internal review decision which is deemed to be refused because that decision was not made within the required time limits.

Search and Retrieval and photocopying fees

Fees may also be charged for search and retrieval of records as follows:

- In respect of personal records, fees in respect of the cost of copying the records requested will apply.
- In respect of other (non-personal) information, fees may be charged in respect of the time spent in efficiently locating and copying records, based on a standard hourly rate of €20.95. No charges shall apply in respect of the time spent by public bodies in considering requests.

A deposit may be payable where the total fee is likely to exceed €50.79. In these circumstances, we will, if requested, assist the member of the public to amend the request so as to reduce or eliminate the amount of the deposit.

Charges may be waived in the following circumstances:

- where the cost of collecting and accounting for the fee would exceed the amount of the fee; or
- where the information would be of particular assistance to the understanding of an issue of national importance; or
- in the case of personal information, where such charges would not be reasonable having regard to the means of the requester.

Section 47 of the FOI Act sets out the rules for applying search and retrieval fees. Fees are currently set as follows in accordance with Statutory Instruments Nos. 264 of 2003, 139 of 1998 and 13 of 1997:

- €20.95 per hour - search and retrieval
- €0.04 per sheet for a photocopy
- €0.51 for a 3½ inch computer diskette
- €10.16 for a CD-ROM

Departmental Structure of the National Cancer Registry

The National Cancer Registry is divided up into four functional Departments. All Departments carry a reporting relationship to the Director who has ultimate responsibility for implementation of the Board's policies.

Departments

Administration Department

Information Technology Department

Data Department

Research Department

Administration Department

The head of this department is the Director of the Registry who is responsible for implementation of the Board's policy.

Functions of the Administration Department

- ◆ Corporate & Strategic Planning
- ◆ Policy Formulation
- ◆ Legal & Statutory Obligations
- ◆ Consultation & co-operation with external bodies
- ◆ Administrative Services for the Board
- ◆ Finance and Accounting including superannuation
- ◆ Human Resource Management including recruitment, training, & staff relations
- ◆ Health & Safety
- ◆ Public Relations & corporate communication including, media relations, production of corporate newsletters & provision of content for website
- ◆ Event Management including, report launches, press conferences and conference organization
- ◆ Freedom of Information
- ◆ Publications
- ◆ General Administration including responsibility for premises and office supplies.

Delivery of Service

The services delivered by the Administration Department are corporate management services for the entire Registry. This includes finance, HR, PR and general administration. Requests for information under the Freedom of Information Act, 1997 are also delivered through this department but must state that the request is being made under the Freedom of Information Act, 1997.

Contact details:

| | | |
|---|--|--|
| Dr Harry Comber Tel 021-4548801 | Director Fax 021-4318016 | email h.comber@ncri.ie |
| Ms Irene O'Driscoll Tel 021-4548804 | Administrator Fax 021-4318016 | email i.odriscoll@ncri.ie |
| Ms Geraldine Finn Tel 021-4548803 | Communications & HR Officer Fax 021-4318016 | email g.finn@ncri.ie |
| Mr Christopher Smith Tel 021-4548805 | Executive Assistant Fax 021-4318016 | email c.smith@ncri.ie |

Classification of Records Held in Administration Department

- ◆ Files Relating to Legal and Statutory Obligations including statutory instruments
- ◆ Strategic Management Records
- ◆ Income & Expenditure Accounts
- ◆ Procurement Records
- ◆ Minutes of Board Meetings
- ◆ Fixed Asset Register
- ◆ Salaries & Pensions Records
- ◆ Correspondence from Department of Health & Other Bodies
- ◆ Job Descriptions & Interview Records
- ◆ Contracts of Employment
- ◆ Application Forms & CVs
- ◆ Job Evaluation Records
- ◆ Staff Manual
- ◆ Training Records
- ◆ Safety Statement
- ◆ Health & Safety Reports
- ◆ Confidentiality Agreements
- ◆ Press Releases
- ◆ Freedom of Information Requests & Responses
- ◆ Section (15) and Section (16) FOI Information Manuals
- ◆ Content for Website

Information Technology Department

The first registration system was designed towards the end of 1993 and became fully operational by 1994. In June 2002 this system was replaced by a more powerful client-server application which was also developed in-house.

Functions of the Information Technology Department

- ◆ Planning, development, management and delivery of IT services
- ◆ Systems design & development
- ◆ Fostering links with other health agencies for the effective delivery of operational and other strategic IT services
- ◆ Development of interfaces between the Registry and hospital information systems
- ◆ Development and Implementation of formal methods of quality control within Information technology
- ◆ Development and maintenance of communication protocols between the Registry and other data sources
- ◆ Maintenance of IT Security Systems
- ◆ Purchasing of all IT equipment
- ◆ Hardware and software inventory control
- ◆ Delivery of IT training for Registry staff
- ◆ Documentation of IT policies, procedures

Delivery of Services

The Information Technology Department develops and maintains an I.T. Infrastructure to support the operations of other Departments within the Registry. There is no direct service delivery between this department and the general public.

Contact details:

| | | |
|-------------------------------------|---|--|
| Ms Alicia Magner Tel 021-4548831 | Information Technology Specialist Fax 021-4318016 | email a.magner@ncri.ie |
| Ms Anne Griffin Tel 021-4548830 | IT Administrator Fax 021-4318016 | email a.griffin@ncri.ie |
| Mr Alan Gibson Tel 021 4548835 | Infrastructure Development Officer Fax 021-4318016 | email a.gibson@ncri.ie |
| Mr Damien Foley Tel 021-4548815 | Analyst Programmer Fax 021-4318016 | email d.foley@ncri.ie |

Classification of Records Held in Information Technology Department

- ◆ Database Model
- ◆ Data Dictionary
- ◆ Correspondence from External IT Companies
- ◆ Interactive Help System Database
- ◆ Requirement Specifications
- ◆ Design Specifications
- ◆ Project Plans
- ◆ IT Policy Documents
- ◆ Project Progress Reports
- ◆ Software Register
- ◆ Hardware Register
- ◆ User Manuals
- ◆ Internal Administrative Files

Data Department

Data comes from two main sources: case records collected in hospitals and death certificates collected at central statistics office. All data is registered electronically at source using database replication technology and transmitted over a secure encrypted tunnel (VPN) to the registry head office in Cork. Here it is checked for accuracy and consistency and merged with existing data. Duplicate registrations are merged or removed and the data is prepared for analysis and reporting. Data from the National Cancer Registry, Ireland has been included in EUROCIM, EUROCARE 3, EUCAN, ACCIS and "Cancer in Five Continents" datasets. Acceptance of data for inclusion in all international datasets is contingent on strict quality checks at the International Centre for Research on Cancer (IACR) in Lyon, France.

Functions of the Data Department

- ◆ Data collection of all newly diagnosed cancer cases in the Republic of Ireland.
- ◆ Data collection of all deaths from cancer in the Republic of Ireland.
- ◆ Coding of diagnoses and procedures using ICD-O coding standards.
- ◆ Data management and quality control in line with standards set by the International Association of Cancer Registries and the European Network of Cancer Registries.
- ◆ Preparation of data for annual reports on cancer incidence in Ireland.
- ◆ Provision of datasets to external users for research purposes.
- ◆ Supporting various internal research projects.
- ◆ Maintaining contact with other cancer registries.

Delivery of Service

Although not delivering a service directly to the public many activities of this Department are of general interest to the public including the collection, management and analysis of the data that makes up the National Database on Cancer Incidence and Mortality.

Contact details:

| | | |
|---|--|--|
| Ms Mary Chambers Tel 021-4548810 | Data Manager Fax 021-4318016 | email m.chambers@ncri.ie |
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A full list of Tumour Registration Officers and their locations is included in Appendix 2

Classification of Records Held in Data Department

- ◆ National Database on Cancer Incidence & Mortality
- ◆ Policies & Procedures on International Coding Standards
- ◆ Policy Documents on Data Collection
- ◆ Records of Meetings with External Bodies
- ◆ Records of Data Group Meetings
- ◆ Records of Internal Training Courses
- ◆ User Manuals
- ◆ Progress Reports
- ◆ Work Plans for Tumour Registration Officers

Research Department

The National Cancer Registry has an active research programme covering cancer aetiology, diagnosis, treatment and survival. Most of this research has been presented in the reports of the registry. The research department provides all output from the National Cancer Registry. The registry has produced an annual statistical report every year since 1994 and three joint reports have been produced with the Northern Ireland Cancer Registry - 'Cancer in Ireland 1994-1996', 'All-Ireland Cancer Statistics 1998-2000' and Cancer in Ireland 1994-2002.

Two fellowships in cancer epidemiology were funded in 2001 by the Health Research Board and the Northern Ireland Research & Development office in Belfast. One of these fellows is now employed as an epidemiologist at the National Cancer Registry in Cork and the other is based at the Department of Public Health & Epidemiology in Queens University in Belfast following an initial year at the National Cancer Institute in Maryland USA.

A considerable amount of work was done by the research department of the registry in carrying out analysis of existing data and reporting to the Expert Group on Radiotherapy Services in looking at current patterns of provision of services and projection of caseload by health board to 2015.

Functions of Research Department

- ◆ Production of Annual Statistical Reports
- ◆ Production of Research Papers and Presentations
- ◆ Management of various projects on cancer incidence, mortality and survival
- ◆ Responses to Queries
- ◆ Provision of Datasets

Delivery of Service

The Research Department delivers a service through the publication of papers and reports relating to cancer incidence, mortality, treatment and survival. This department also delivers an information service to the general public. Requests for information can be sent by email to s.deady@ncri.ie. A list of publications, as well as on-going and planned research is listed in Appendix 1 of this manual.

Contact details:

| | | |
|--|--|--|
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| Mr Joe McDevitt Tel 021- | Statistical Analyst Fax 021-4318016 | email j.mcdevitt@ncri.ie |
| Ms Maria Kelly Tel 021-4548829 | Analyst/Researcher Fax 021-4318016 | email m.kelly@ncri.ie |
| Ms Mairead Skally Tel 021- | Researcher Fax 021-4318016 | email m.skally@ncri.ie |

Classification of Records Held in Research Department

- ◆ Completed Reports and Projects
- ◆ Draft Reports
- ◆ Completed Presentations
- ◆ Grant Applications
- ◆ Query Responses
- ◆ Records of Research Work in Progress

Appendix 1

Recent publications – for complete list go to:-

<http://www.ncri.ie/pubs/pubs.shtml>

Reports

Carsin AE, Sharp L, Comber H.

An atlas of cancer in Ireland 1994-2003. 170 pages.
National Cancer Registry Ireland, Cork. 2009.

Donnelly DW, Gavin AT, Comber H.

Cancer in Ireland 1994-2004: A comprehensive report. 337 pages.
Northern Ireland Cancer Registry, Belfast / National Cancer
Registry Ireland, Cork. 2009.

National Cancer Registry Ireland.

Cancer in Ireland 1994-2005: a summary. 4 pages.
National Cancer Registry Ireland, Cork. 2007.

National Cancer Registry Ireland.

Trends in Irish cancer incidence 1994-2002 with projections to 2020. 62 pages.
National Cancer Registry Ireland, Cork. 2006.

O'Lorcain P, Comber H, Walsh PM.

Trends in Irish cancer mortality rates 1950-2002 with predictions to 2015. 190 pages.
National Cancer Registry Ireland, Cork. 2006.

Walsh PM, Comber H.

Patterns of care and survival of cancer patients in Ireland 1994 to 2001: time-trends and regional
variation for breast, colorectal, lung and prostate cancer. 207 pages.
National Cancer Registry Ireland, Cork. 2006.

Women's Health Council, National Cancer Registry Ireland.

Women and cancer in Ireland 1994-2001. 208 pages.
The Women's Health Council, Dublin and National Cancer Registry Ireland, Cork. 2006.

Quinn M, Wood H, Cooper N, Rowan S.

Cancer atlas of the United Kingdom and Ireland 1991-2000. 414 pages.
National Statistics Studies on Medical and Population Subjects No. 68.
Palgrave Macmillan, Basingstoke, Hampshire, 2005.

Comber H, Deady S.

Cancer in County Louth.
National Cancer Registry Ireland, Cork. 2004.

Campo J, Comber H, Gavin AT

All-Ireland cancer statistics 1998-2000.
National Cancer Registry Ireland, Cork, and Northern Ireland Cancer Registry, Belfast, 2004.

Peer-reviewed publications – for complete list go to:-

<http://www.ncri.ie/pubs/pubs.shtml>

Drummond FJ, Carsin AE, Sharp L, Comber H.

Trends in prostate specific antigen testing in Ireland: lessons from a country without guidelines.
Ir J Med Sci. 2009 Jun 27. [Epub ahead of print]
PMID: 19562407 [PubMed - as supplied by publisher]

Drummond FJ, Carsin AE, Sharp L, Comber H.

Factors prompting PSA-testing of asymptomatic men in a country with no guidelines: a national survey of general practitioners.
BMC Fam Pract. 2009; 10(1):3.
PMID: 19138385 [PubMed - indexed for MEDLINE]

Falebita OA, Mancini S, Kiely E, Comber H.

Rising incidence of renal cell carcinoma in Ireland.
Int Urol Nephrol. 2009; 41(1):7-12.
PMID: 18566909 [PubMed - indexed for MEDLINE]

Carsin AE, Sharp L, Cronin-Fenton DP, Céilleachair AO, Comber H.

Inequity in colorectal cancer treatment and outcomes: a population-based study.
Br J Cancer. 2008;99(2):266-74.

Coleman MP, et al.; CONCORD Working Group.

Cancer survival in five continents: a worldwide population-based study (CONCORD).
Lancet Oncol. 2008;9(8):730-56.

Donnelly M, Anderson LA, Johnston BT, Watson RG, Murphy SJ, Comber H, McGuigan J, Reynolds JV, Murray LJ.

Oesophageal cancer: caregiver mental health and strain.
Psychooncology. 2008. [Epub ahead of print]

Drummond FJ, Sharp L, Carsin AE, Kelleher T, Comber H.

Questionnaire order significantly increased response to a postal survey sent to primary care physicians.
J Clin Epidemiol. 2008;61(2):177-85.

Falebita OA, Mancini S, Kiely E, Comber H.

Rising incidence of renal cell carcinoma in Ireland.
Int Urol Nephrol. 2008. [Epub ahead of print]

Anderson LA, Murphy SJ, Johnston BT, Watson RG, Ferguson HR, Bamford KB, Ghazy A, McCarron P, McGuigan J, Reynolds JV, Comber H, Murray LJ.

Relationship between *Helicobacter pylori* infection and gastric atrophy and the stages of the oesophageal inflammation, metaplasia, adenocarcinoma sequence: results from the FINBAR case-control study.

Gut. 2008;57(6):734-9.

Berrino F, et al.; EUROCARE Working group.

Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995-99: results of the EUROCARE-4 study.

Lancet Oncol. 2007;8(9):773-83.

Cronin-Fenton DP, Sharp L, Carsin AE, Comber H.

Patterns of care and effects on mortality for cancers of the oesophagus and gastric cardia: a population-based study.

Eur J Cancer. 2007;43(3):565-75.

Murphy SJ, Hughes AE, Patterson CC, Anderson LA, Watson RG, Johnston BT, Comber H, McGuigan J, Reynolds JV, Murray LJ.

A population-based association study of SNPs of GSTP1, MnSOD, GPX2 and Barrett's esophagus and esophageal adenocarcinoma.

Carcinogenesis. 2007;28(6):1323-8

O'Lorcain P, Comber H.

Prostate cancer mortality predictions for Ireland up to 2015.

Eur J Cancer Prev. 2007;16(4):328-33.

O'Lorcain P, Walsh PM, Comber H.

Cumulative cancer mortality risk and potential years of life lost to 64 years of age in Ireland, 1953-2002.

Eur J Cancer Prev. 2007;16(3):167-77.

Stack M, Walsh PM, Comber H, Ryan CA, O'Lorcain P.

Childhood cancer in Ireland: a population-based study.

Arch Dis Child. 2007;92(10):890-7.

Verdecchia A, et al.; EUROCARE-4 Working Group.

Recent cancer survival in Europe: a 2000-02 period analysis of EUROCARE-4 data.

Lancet Oncol. 2007;8(9):784-96.

Anderson LA, Johnston BT, Watson RG, Murphy SJ, Ferguson HR, Comber H, McGuigan J, Reynolds JV, Murray LJ.

Nonsteroidal anti-inflammatory drugs and the esophageal inflammation-metaplasia-adenocarcinoma sequence.

Cancer Res. 2006;66(9):4975-82.

Cronin-Fenton DP, Sharp L, Deady S, Comber H.

Treatment and survival for non-Hodgkin's lymphoma: influence of histological subtype, age, and other factors in a population-based study (1999-2001).

Eur J Cancer. 2006;42(16):2786-93.

Moloney FJ, Comber H, O'Lorcain P, O'Kelly P, Conlon PJ, Murphy GM.

A population-based study of skin cancer incidence and prevalence in renal transplant recipients.

Br J Dermatol. 2006;154(3):498-504.

O'Lorcain P, Comber H.

Mortality predictions for Ireland, 2001-2015: cancers of the breast, ovary, and cervix and corpus uteri.

Int J Gynecol Cancer. 2006;16 Suppl 1:1-10.

O'Lorcain P, Deady S, Comber H.

Mortality predictions for colon and anorectal cancer for Ireland, 2003-17.

Colorectal Dis. 2006;8(5):393-401.

O'Lorcain P, Deady S, Comber H.

Mortality predictions for esophageal, stomach, and pancreatic cancer, Ireland, up to 2015.

Int J Gastrointest Cancer. 2006;37(1):15-25.

Walsh PM, McCarron P, Middleton RJ, Comber H, Gavin AT, Murray L.

Influence of mammographic screening on trends in breast-conserving surgery in Ireland.

Eur J Cancer Prev. 2006;15(2):138-48.

Comber H, Cronin DP, Deady S, Lorcain PO, Riordan P.

Delays in treatment in the cancer services: impact on cancer stage and survival.

Ir Med J. 2005;98(8):238-9.

Comber H, Gavin A.

Recent trends in cervical cancer mortality in Britain and Ireland: the case for population-based cervical cancer screening.

Br J Cancer. 2004;91(11):1902-4.

O'Lorcain P, Comber H.

Lung cancer mortality predictions for Ireland 2001-2015 and current trends in North Western Europe.

Lung Cancer. 2004;46(2):157-63.

Montanaro F, et al.; ENCR Working Group.

Pleural mesothelioma incidence in Europe: evidence of some deceleration in the increasing trends.

Cancer Causes Control. 2003;14(8):791-803.

Mahmud SM, Reilly M, Comber H.

Patterns of initial management of lung cancer in the Republic of Ireland: a population-based observational study.

Lung Cancer. 2003;41(1):57-64.

Appendix 2

Tumour Registration Officers and their base locations

| | |
|----------------------------------|--|
| 1. Ms Margaret Burgess | Regional Hospital – Waterford |
| 2. Ms Kate Burke | National Cancer Registry - Cork |
| 3. Ms Mairead Casey | Tallaght Hospital – Dublin |
| 4. Ms Margaret Cawley | University College Hospital – Galway |
| 5. Ms Ursula Cullen | St James's Hospital – Dublin |
| 6. Ms Michelle Deffew-McClintock | Tullamore General Hospital - Co Offaly |
| 7. Ms Maria Duane | National Cancer Registry – Cork |
| 8. Ms Philomena Gallagher | Mater Hospital - Dublin |
| 9. Ms Sharon Glynne | Navan General Hospital - Co Meath |
| 10. Ms Grace Gregan | National Cancer Registry - Cork |
| 11. Ms Eve Horan | St Lukes Hospital – Dublin |
| 12. Ms Katherine Leonard | St James's Hospital – Dublin |
| 13. Ms Eileen Menarry | General Hospital - Sligo |
| 14. Ms Martina McCarthy | St Vincent's Hospital – Dublin |
| 15. Ms Terry Stapleton | Mid-Western Regional Hospital - Limerick |
| 16. Ms Mary-Lou Holohan | St Vincent's Hospital - Dublin |
| 17. Ms Hazel Southern | Mater Private Hospital – Dublin |
| 18. Ms Geraldine Smith | St Vincent's Private Hospital – Dublin |
| 19. Ms Mary Byrne | University College Hospital – Galway |
| 20. Ms Alice O'Donnell | Letterkenny General Hospital - Donegal |