Cancer in Ireland 1994-1998

- incidence
- mortality
- treatment
- survival

History of cancer registration in Ireland

- Southern Tumour Registry 1972
- Working Party 1989
- National Cancer Registry Board 1991
- Director appointed 1992
- Development plan approved 1993
- Registration began 1994
International structure

Associations
• International Association of Cancer Registries
• European Network of Cancer Registries
• SEER
• NAACCR
• UKACR

Agencies
• International Agency for Research on Cancer
• National Cancer Institute/SEER
• CDC
• ONS
• UICC

Publications
• Cancer Incidence in Five Continents (vol. 7)
• EUROCare

Databases
• EUROs
• EUCAN
• GLOBOCAN

• International agreements on
  – coding
  – classification
  – methods
  – analysis
• Training
• Audit
• Software
• Manuals
The National Cancer Registry

- Covers Republic of Ireland
- Population base 3.6 M
- 20,000 cancer registrations per year (6/1000)
  - 165000 registrations
- 7,500 cancer deaths per year (2/1000)
  - 50000 cancer deaths

At present

<table>
<thead>
<tr>
<th>year</th>
<th>cases</th>
<th>cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>21651</td>
<td>20197</td>
</tr>
<tr>
<td>1995</td>
<td>21670</td>
<td>20152</td>
</tr>
<tr>
<td>1996</td>
<td>22878</td>
<td>21290</td>
</tr>
<tr>
<td>1997</td>
<td>23780</td>
<td>22133</td>
</tr>
<tr>
<td>1998</td>
<td>23899</td>
<td>22086</td>
</tr>
<tr>
<td>1999</td>
<td>24129</td>
<td>21716</td>
</tr>
<tr>
<td>2000</td>
<td>21297</td>
<td>10582</td>
</tr>
<tr>
<td>2001</td>
<td>5503</td>
<td>1787</td>
</tr>
</tbody>
</table>
Functions


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;

Functions (contd.)

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;

   • To furnish advice, information and assistance in relation to any aspect of such service to the Minister.

The Registry is obliged to collect this data, but there is no obligation on any person or institution to co-operate.
Structure

- Administered by National Cancer Registry Board
- Funded by Department of Health and Children
- Based in Cork—close ties to UCC
- Annual budget £IR900K
- Full-time staff 27

Staffing

- Data collection 18
- Supervision, checking, processing 2.5
- IT 2
- Analysis and reporting 2.5
- Administration 2

Total (FTE) 27
Data held

- all new cancers in Ireland 1994-1998
- all deaths in Ireland 1994-1999
- all cancers in Ireland and N. Ireland 1994-1996

Most of this data is freely available subject to confidentiality constraints
- on request
- on website

Data collection
Pathology report → Medical record → Treatment data → Checking → Transmission to Registry → Checking → Duplicate checking → Merging - patients tumours treatments → Data acquisition by the Registry

Sources of registrations

- Tumour registration officers 98%
- Death certificates 2%
- Direct reporting 0.3%

Registry
Hospital sources of data

- pathology reports
- patient discharge data (HIPE)
- radiotherapy
- other inpatient sources
- other outpatient sources

Data processing

- notification of a case
- check for previous registration
- other information sources
- complete registration
- ship data to Cork
- check for errors and consistency
- check for duplicate patients and tumours
- return queries
- add to central database
- periodic batch checks
- quality assessment and reporting analysis
Data collected

hierarchical model

patient

<table>
<thead>
<tr>
<th>tumour</th>
<th>tumour</th>
<th>tumour</th>
</tr>
</thead>
<tbody>
<tr>
<td>treatment</td>
<td>treatment</td>
<td>treatment</td>
</tr>
<tr>
<td>treatment</td>
<td>treatment</td>
<td>treatment</td>
</tr>
</tbody>
</table>

Patient information

name - surname, first, other address
other address(es)
ward/DED of residence*
GMS number
RSI/PPS number
date of birth
sex
screening status

smoking status
marital status
occupation
occupational status
alive or dead*
date of death*
cause of death*
place of death*

* added by data linkage
Tumour information

- source of notification
- method of presentation
- GP
- hospital
- consultant
- medical record number
- incidence date
- age at incidence
- topography
- morphology
- grade

- behaviour
- method of diagnosis
- TNM stage
- basis of staging
- residual disease
- sites of metastases
- pathologist
- histology date
- laboratory and reference number
- tumour markers
- recurrence
- delays

Treatment information

At present only initial treatments are recorded

- treatment type
- treatment date
- hospital
- consultant
- admission type
- treatment intent
- place of treatment
Quality control

- staff and training
- re-abstraction
- consistency checks
- sample inspections

Uses of data

- research
- planning
- audit
- education
Services provided

- raw data
- scheduled reports
- ad hoc reports
- research projects

Raw data

- on web site
- IACR/IARC datasets
- death certificates
- north/south dataset
- SEERStat dataset
Output

- Scheduled reports
  - Annual incidence reports
  - All-Ireland report 1994-1996
  - Public health information system

- Ad hoc reports
  - Responses to enquiries
    - Department of Health and Children
    - clinicians
    - nurses
    - public
  - Information service to Regional Directors of Cancer Services/health boards

Ad hoc reports per month

![Graph showing ad hoc reports per month from February to November.](image)
Research

• treatment and survival variation
• time trends in mortality
• delays in diagnosis and treatment
• aetiology of oesophageal cancer
• urban/rural differences in skin cancer
• cancer in transplant patients
• late presentation of breast cancer
• Louth project
• north-south comparison of survival

Descriptive epidemiology

• Quantify risk
• Variation in risk with
  – personal characteristics
  – place
  – time
Variation in risk

- person
  - gender
  - age
  - occupation

Malignant cancers 1994-1998

<table>
<thead>
<tr>
<th></th>
<th>female</th>
<th>male</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>cases per year</td>
<td>8149</td>
<td>8946</td>
<td>17095</td>
</tr>
<tr>
<td>% of all registered neoplasms</td>
<td>82%</td>
<td>94%</td>
<td>88%</td>
</tr>
<tr>
<td>cumulative risk (0 - 74 yrs)</td>
<td>30%</td>
<td>36%</td>
<td></td>
</tr>
<tr>
<td>crude rate (per 100,000)</td>
<td>446</td>
<td>497</td>
<td></td>
</tr>
<tr>
<td>European age-standardized rate</td>
<td>443</td>
<td>576</td>
<td></td>
</tr>
<tr>
<td>mortality/ incidence ratio</td>
<td>0.42</td>
<td>0.45</td>
<td>0.43</td>
</tr>
</tbody>
</table>
Common cancers 1994-1998

Age-specific incidence rates 1994-1998
Patients aged under 65 at diagnosis

- Breast: 62% females, 39% males
- Melanoma: 60% females, 58% males
- Lymphoma: 52% females, 63% males
- Leukaemia: 46% females, 47% males
- Colorectal: 31% females, 34% males
- Stomach: 24% females, 33% males
- Lung: 27% females, 30% males
- Bladder: 29% females, 29% males
- Prostate: 16% females, 41% males

% of expected

- Garda Síochána
- Army
- Health
- Other gainful
- Scientific and technical
- Other manufacturing
- Communication etc.
- Religious
- Food, drink and tobacco
- Farming, fishing and building and construction
- Central and local electrical trades
- Business and commerce
- Clerical and office
- Personal service and teachers
- Chemical, paper etc.
- Textile, clothing and leather
- Engineering and allied
- Other professional
- Sales occupations
- Social workers and related managers and executives
- Computer software
Variation in risk

- place
  - international
  - local
Cancer incidence in Ireland and Europe
-all malignant cancers except skin
cases per 100,000
(European standardised)

<table>
<thead>
<tr>
<th>Country</th>
<th>Year</th>
<th>female</th>
<th>male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ireland</td>
<td>1994–98</td>
<td>319</td>
<td>391</td>
</tr>
<tr>
<td>Scotland</td>
<td>1997</td>
<td>369</td>
<td>456</td>
</tr>
<tr>
<td>Wales</td>
<td>1997</td>
<td>355</td>
<td>430</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>1997</td>
<td>339</td>
<td>415</td>
</tr>
<tr>
<td>England</td>
<td>1997</td>
<td>328</td>
<td>385</td>
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<tr>
<td>European Union</td>
<td>1996</td>
<td>292</td>
<td>416</td>
</tr>
</tbody>
</table>

Lung cancer incidence and deprivation

![Graph showing lung cancer incidence and deprivation index](image)
Variation in risk

- time
Annual percentage change in mortality:

Annual percentage change in rates:

all patients

male EASIR

female EASIR

male EASMR

female EASMR
Cancer surveillance

- registration->surveillance
- all aspects of cancer control
  - risk factors
  - diagnosis
  - treatment
  - outcome
Patients treated for bowel cancer

Surgery for bowel cancer
Influence of age on treatment for bowel cancer

Cancer survival at five years
Influence of age on colorectal cancer survival

Influence of stage on colorectal cancer survival
Mortality/incidence ratio 1996
-all cancers except skin

Mortality/incidence ratio 1996
-bowel cancer
Relative survival -bowel cancer

Sweden
Austria
Spain
Ireland*
Germany
N Ireland*
Finland*
France
Netherlands
Italy
Scotland*
Denmark*

*national registries

WHO rankings

disability adjusted life years

France
Sweden
Spain
Italy
Greece
Switzerland
Netherlands
United Kingdom
Norway
Belgium
Austria
Luxembourg
Iceland
Finland
Germany
Ireland
Denmark
Portugal
What is needed?

• higher quality inputs
  – comprehensive
  – timely
• higher quality outputs
• change in behaviours as a result

What is needed?

• Data
  – linkage
  • other hospital data—HIPE, costs, follow-up
  • occupation and industry
  • social indicators
  • census data
  • death certificates
  • geographical/environmental data
What is needed?

• Data
  – Communications infrastructure
    • high speed inter-hospital links
    • electronic transfer of patient data
    • standardisation of hospital IT systems
  – Establish rights to data
    • legal clarification
    • patient and community rights

What is needed?

• Analysis
  – pool of expertise
  – clear objectives
  – low cost access to
    • maps
    • census data
    • geocoding
  – link to policy objectives and implementation
Proposals

• National cancer surveillance system
  – rapid data service to
    • health professionals
    • planners and managers
    • patients and general public
  – risk factor monitoring
  – trends and progress in cancer control
  – more formal link to decision-making
    • Department of Health and Children
    • National Cancer Forum
    • health boards

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