



*National Cancer Peer Review
Programme 2004-2007*

Cancer Peer Review Report
Northern Ireland Cancer Registry

Cancer Registries Peer Review Team
January 2008

Reader Information

| | |
|------------------------------|---|
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1 INTRODUCTION

1.1 The National Peer Review Programme for Cancer Registration

The National Peer Review Programme for Cancer Registration aims to improve the processes, timeliness, quality and information provision for cancer, to enable the planning and monitoring of cancer services, by:

- ensuring services are as secure and effective as possible;
- improving the quality of registration;
- improving the availability and usefulness of information which registries produce;
- undertaking independent, fair reviews of services;
- providing development and learning for all involved;
- encouraging the dissemination of good practice.

The outcomes of National Peer Review Programme for Cancer Registration are:

- confirmation that cancer registration services are of approved quality;
- speedy identification of major shortcomings in the quality of cancer registration services where they occur, so that rectification can take place;
- published reports that provide accessible public information about the quality of cancer registration services;
- used to inform and be informed by on-going quality monitoring and enhancement

1.2 Background and context

The National Peer Review Programme for Cancer Registration is underpinned by the Manual for Cancer Services 2004, which now includes specific measures for cancer registries. The cancer registry measures incorporate the recommendations contained within relevant national publications.

The Healthcare Commission (HCC) supports the aims of the Cancer Action Team's National Cancer Peer Review Programme, and intends to monitor health organisations' progress in implementing findings from the reviews.

1.3 The Peer Review process

The process leading to the publication of this report has been one of peer review, carried out by teams of professional peers and service user reviewers. Wherever possible the professional peers have been those trained and working in the same discipline as those they have reviewed. Peer review therefore enables assessments to be made by those who understand cancer registration. It also enables assessments to be credible and to command the respect of those being reviewed.

The peer review process consists of the following three key stages:

- Pre-assessment - to include a self-assessment of the degree of compliance against the cancer registration measures contained within the Manual for Cancer Services.
- The peer review visit to a Cancer Registry, which provides the opportunity for a more qualitative assessment.
- Agreement of remedial action against a clear timetable of implementation and follow up, and dissemination of good practice.

Reviewers are asked to consider the themes of Leadership, Corporate Governance, Workforce, Service Improvement, and Facilities and also to make any general points with regard to the teams and services. Those areas will be explored in the summary below.

Reviewers are also asked to note areas of immediate concern, further consideration or concern, or good practice.

Full details of the process of National Peer Review for Cancer Registration can be found in the *Handbook for the National Peer Review Process for Cancer Registration*.

The report is divided into chapters showing the compliance by each topic. The percentage compliance is given against the level 1* measures and also the level 1 & 2 measures. Level 1* measures are those measures that are “fundamental to the delivery of a satisfactory service”, level 1 & 2 measures “reflect progressive development in the quality of the service.” This distinction is designed to assist in prioritising remedial actions.

A general expectation underpinning the agreed remedial action is that, over time, full compliance with the measures will be achieved. Compliance determinations for each measure are available on the Cancer Quality Information Network System (CQuINS), which is also designed to help teams monitor and report progress with measures’ compliance. The Registry’s remedial action in response to this Report will also be available on the CQuINS website www.cquins.nhs.uk

2 **ACKNOWLEDGEMENTS**

We would like to take this opportunity to thank the many people involved in the process, across the reviewed organisation and within the review teams, for their hard work, energy and dedication to working together to improve cancer registration services in Northern Ireland and to share the good practice that already exists.

We are grateful to the Registry for provision of the Context section of this report, which was supplied prior to the review visit. We also like to thank NHS and voluntary organisations for releasing staff to become Peer Reviewers, without which the programme would not exist.

3 EXECUTIVE SUMMARY

3.1 Context

This report should be read as an overall assessment of the Registry and its functions as they were at the time of the Peer Review visit. There are two main parts to the report section, a quantitative representation of compliance with the Measures and a qualitative commentary which addresses wider issues and identifies concerns and risks, issues for further consideration and examples of good practice. We are grateful to the Registry for provision of the Context section of this report, which was supplied prior to the review visit.

The Peer Review programme was designed for English Cancer Registries based on their registration processes, functionality and governance. Northern Ireland requested to be reviewed and because of the differences between the Northern Ireland Registration system and that of the English registries, not all the Measures were applicable to Northern Ireland. The Review Team were advised of these differences and reviewed the organisation accordingly.

The Northern Ireland Cancer Registry Steering Group, in conjunction with the Department of Health, Social Services and Public Safety (DHSSPS), commissioned the review and subsequent report, but the usage, dissemination and any identified remedial actions remain at the discretion of the organisation and its Steering Group.

3.2 Organisation

The Review Team was impressed by the remarkable achievements made by the Northern Ireland Cancer Registry (NICR) since its inception 13 years ago. Over that time it has established an active cancer intelligence service, firmly embedded in health service provision in Northern Ireland. It is making a real difference to the delivery of patient care and acts as a support and catalyst to clinicians, charities and decision makers.

The commitment, leadership and energy of the Director have been central to these developments. A well organised structure has evolved in combination with support from the DHSSPS and Queen's University Belfast (QUB), which results in high quality cancer intelligence that is both relevant to the local community and at national level. This was endorsed by the Chief Medical Officer at the review meeting. The Steering Group and the Council are functioning well and appropriate financial and managerial governance processes are in place with both the DHSSPS and QUB.

The lack of a clear legal framework for the NICR remains a concern in that, unlike English registries, NICR's activities are not covered by the provisions of Section 60 of the Health and Social Care Act (2001). Agreed UKACR policies are applicable to the NICR, but their interpretation and application in Northern Ireland are not straightforward. This may leave the NICR vulnerable to legal challenges regarding its use of patient identifiable information.

Funding for the Registry comprises a mix of "core" and "project" funding; the organisation has worked hard and efficiently to secure additional funding from several sources. Consideration should be given for the future core funding to include established work programmes (e.g. audits) that have resulted from such innovative projects undertaken by the NICR.

3.3 Registration

The NICR uses a wide range of local electronic data and national electronic sources, including hospital PAS systems, pathology, the national death register and oncology and radiotherapy data sources. The Registry has played an important role in the establishment and validation of primary care cancer registers in Northern Ireland under the terms of the GP contract. The Review Team noted that the NICR does not currently have access to chemotherapy data except via episode data from PAS.

The Registry is actively engaged in negotiations with suppliers of key data sources. Delays in receipt of annual death data are currently being mitigated by the use of quarterly downloads from

the Central Services Agency (CSA). In addition, the Registry is continuing to develop their systems for obtaining data such as addresses, postcode and identification of a patient's General Practitioner to update their records.

There was evidence of a comprehensive Quality Assurance system, with excellent use of automation to support the process, followed by tumour specific and clinical validation. The Review Team commended new data flows from MDTs and the excellent practice of feed back of quality controlled data to the suppliers of the data, as well as the widespread use of the UKACR Training Manual in training staff and relevant external stakeholders.

The Registry has an excellent track record linking with the screening services to monitor patient screening histories since its inception. Regrettably, this enviable position with regard to cervical screening has deteriorated recently, with the Cervical Screening Quality Assurance Reference Centre (QARC) no longer having access to pre 2005 screening histories.

The automated extraction of staging information from pathology reports has been successfully implemented for prostate cancer and malignant melanoma within the NICR; however the applicability of this to the wider registration community would require testing by each local area.

Registry staff reported some occasional difficulties in accessing medical records for validation purposes and that the need for such access may increase with the development of new electronic data feeds from new sources, such as those from the MDT databases. The NICR may benefit from renegotiating Service Level Agreements with relevant organisations.

3.4 Information

The range of outputs produced by the Registry is impressive and includes a series of audit reports, incidence and survival reports, and peer reviewed publications. It has also been successful in securing funding from a range of sources to support the development of scientific studies and peer reviewed audit reports; these activities clearly represent a significant investment of energy, time and organisation. This close collaboration with clinicians has enabled the production of clinically relevant audit reports, which has resulted in changes in clinical practice with benefit to patients. The use of a specialist nurse for management of local genetics requests is practical and effective and enhances further strengthening of clinical links

The NICR has made very good use of its position in the University to develop collaborative research, and has built up links with international bodies creating excellent training opportunities for staff. The Review Team was also impressed by the high profile achieved by the NICR within the health community, but the resultant growing demand for information and intelligence requirement may soon outstrip the resources available.

The NICR is justifiably proud of its website, which contains comprehensive and detailed data and reports and there is evidence of its increasing use by stakeholders.

3.5 Good Practice

The following themes were evident across the topics:

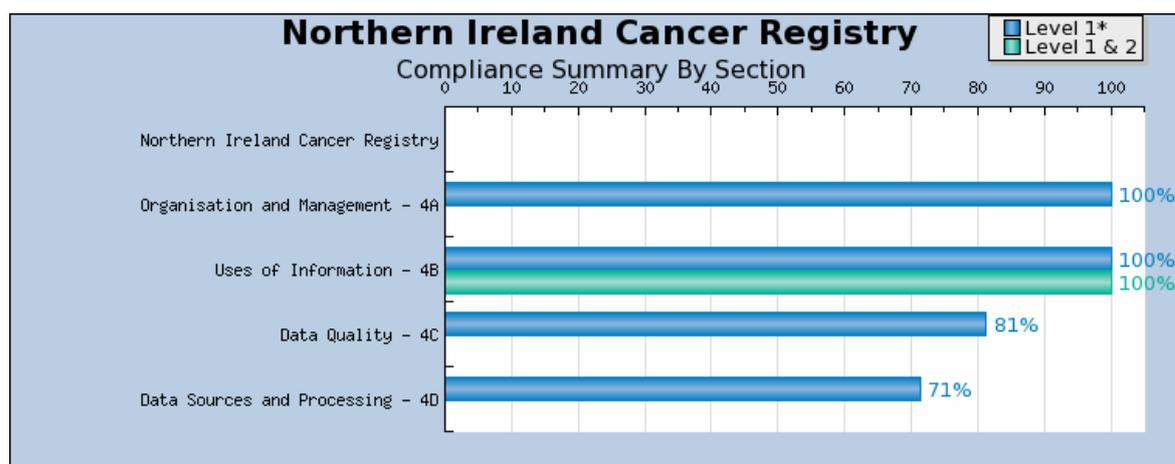
- The high level of engagement with a wide range of stakeholders and the proactive approach to disseminate work and results into the public domain.
- Evidence of strong governance arrangements, financial and managerial, supported by a well established proactive approach to securing additional funding.
- Proactive and innovative use of electronic data and sources to enhance the quality and completeness of their database.
- The extensive and wide range of outputs using the Registry's data, through audit and epidemiological reports, peer reviewed publications and by the Registry's international research collaborations.

4 GRAPHICAL SUMMARY OF REGISTRY COMPLIANCE

| | | |
|-----------------------------|-------------------------------|---------------|
| Registry Contact | Director | Dr Anna Gavin |
| Date of Review Visit | 7 th November 2007 | |

Summary Table

| Code | Topic | % Compliance against Quality Measures | | | |
|------|-----------------------------|---------------------------------------|------|-------|------|
| | | 1* | | 1 & 2 | |
| 4A | Organisation and Management | 12/12 | 100% | - | - |
| 4B | Uses of Information | 6/6 | 100% | 1/1 | 100% |
| 4C | Data Quality | 13/16 | 81% | - | - |
| 4D | Data Sources and Processing | 5/7 | 71% | - | - |



5 CONTEXT

We are grateful to the Registry for provision of this Contextual Report, which was supplied prior to the review visit.

5.1 Registration Area

Northern Ireland consists of the six counties in the north of the island of Ireland and is part of the United Kingdom. The population of Northern Ireland was 1,689,319 at the last census year of 2001. Whereas most of the population is rural, there are two major urban areas situated around the cities of Belfast and Londonderry. The population is relatively racially homogeneous with only a few small ethnic minorities, although there has been a recent influx of immigrants, mainly from Eastern Europe. Northern Ireland has a land border with the Republic of Ireland. The Northern Ireland Cancer Registry is a population-based registry that covers the entire population of Northern Ireland (see map below). There is one Cancer Network covering the area, the Northern Ireland Cancer Network (NICaN).

Map of Northern Ireland



The table below details the Northern Ireland population and the number of annual cancer registrations at the NICR.

| | |
|-------------------------------------|-----------|
| N. Ireland Population (2005) | 1,724,408 |
| Registrations (2005) | |
| All Cancers Including NMSC | 9,390 |
| All Cancers Excluding NMSC | 6,974 |

5.2 Cancer Care Facilities

Most cancer patients are treated within the National Health Service system and even most private patients would receive some of their treatment in National Health Service hospitals. There are 18 hospitals providing acute care located in four regional Health Boards. There is one radiotherapy department located in the Cancer Centre. The vast majority of patients receive all their care within the region. A major re-organisation of cancer services in 1997 introduced the concept and reality of a cancer centre and four cancer units for the population. A major review of Public Administration will result in one Regional Health Authority from April 2008 (to replace the four Health and Social Services Boards). It also saw the amalgamation of 13 Health and Social Care Trusts into 5 Super Trusts on 1 April 2007.

5.3 Differences to the English Cancer Care System

- Northern Ireland has its own Registrar General's Office which provides the Cancer Registry with information on all deaths (via the Department of Health, Social Services and Public Safety (DHSSPS)) and, whilst there are statisticians in the Northern Ireland Statistics and Research Agency (NISRA) within the DHSSPS, there is no cancer registration function similar to that in the Office for National Statistics (ONS) in England.
- A Master Patient Index for all patients registered with a General Practitioner is held at the Central Services Agency (CSA). There are arrangements with the CSA for annual checking of the demographic details of patients registered i.e. most up to date address, postcode, GP Practice and date of death. In addition the CSA reformat the Registry's address data using the 'quick address' software. A tracing service is not provided.
- The Registry has no legal basis; clause 60 of the Health and Social Care Act does not apply in Northern Ireland. A consultation process originated by DHSSPS in 2001 has recently reported with the establishment of a Northern Ireland Privacy Advisory Committee. This lack of a legislative framework, whilst putting data acquisition at risk, is also reducing the use of NICR data e.g. in the Northern Ireland Longitudinal Study.

5.4 Registry Structure

The current Northern Ireland Cancer Registry was established in 1994 to provide information on cancers occurring in the Northern Ireland population for the purposes of research, education and the planning of services. The organisation currently has data from 1993 to 2005 [see www.qub.ac.uk/nicr].

5.4.1 Governance

The Registry is located in Queen's University Belfast (QUB) on the site of the Royal Victoria Hospital. It is funded by an annual grant from the DHSSPS with five yearly reviews to ensure quality and to advise on direction. Each year Business Plans / Annual Reports are produced [see www.qub.ac.uk/nicr].

The Registry is supported by a Management Group / Steering Group that oversees the work of the Registry and a Council appointed by the Management Group, which consists of representatives of the major clinical areas, the DHSSPS, the School of Medicine and Dentistry of QUB, the four Directors of Public Health, the Director of the National Cancer Registry of the Republic of Ireland and a UK Cancer Registry Director (currently David Brewster), relevant voluntary organisations and patient representatives via the Health and Social Care Councils. The function of the Council is to advise the Director and the Management Group on matters relating to the Registry, particularly its outputs.

5.4.2 *Staffing*

Director – 1 WTE with Senior Lecturer duties within the University

Data Manager – 1WTE

IT Staff – 3 WTE plus 1 WTE undergraduate student (1 year placement)

Biostatisticians – 2 WTE plus 1 WTE on secondment from NISRA

Tumour Verification Officers (TVOs) – 4.2 WTE plus 3.8 on research funding (2.8 Audit) plus 1 WTE on Barrett's project

Secretarial staff – 1.2 WTE

Clinical Liaison – 0.8 WTE – (grant funded)

Research Professor – 0.3 WTE

5.4.3 *Method of Operation*

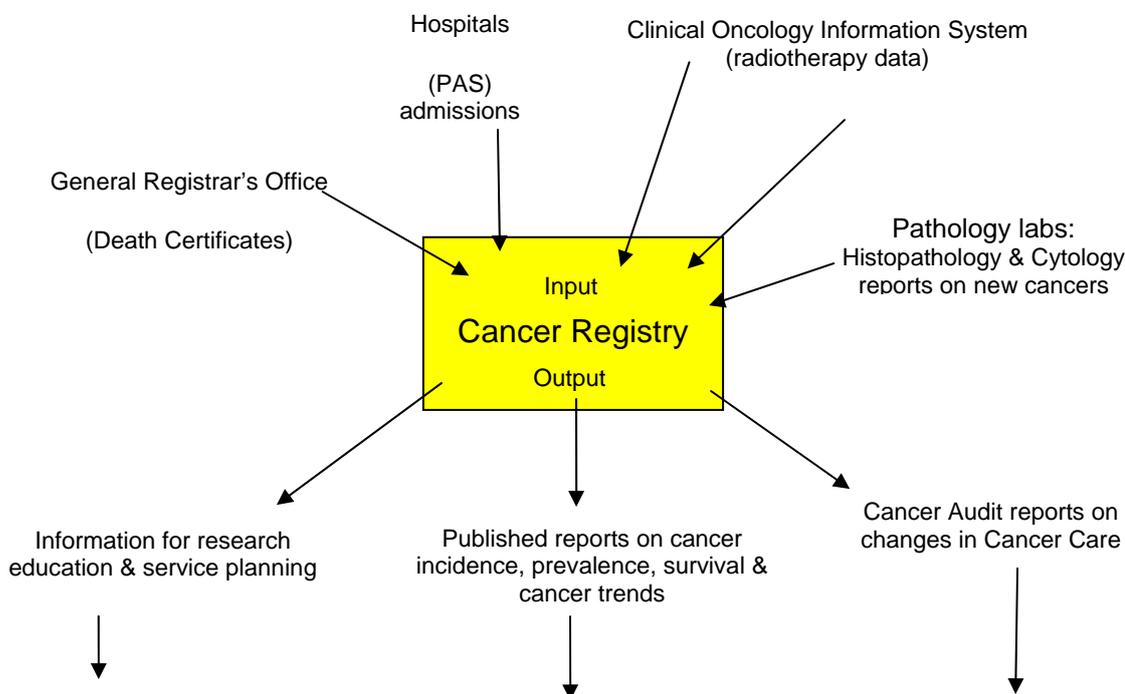
The Registry receives all its data electronically and uses the PRAXIS cancer registration system, in common with four other UK Registries. The NICR has played an active role in the development and evaluation of the PRAXIS system particularly the electronic data capture elements.

The Registry uses three main sources for registration; the Patient Administration System (PAS) used by all the Hospital Trusts, death registrations and histopathology reports from five laboratories covering all of Northern Ireland. Additional minor data sources include hospices while the Clinical Oncology Information System (COIS) provides data on radiotherapy. The text of all pathology reports is received electronically and used by the Registry to validate diagnosis, pathological stage and tumour grade when required. A new development has been the use of the PERL programming language to construct scripts that perform simple keyword searches in order to electronically extract additional data from the pathology text reports. PERL provides powerful pattern matching capabilities and is relatively simple to use. So far the technique has been successfully applied to the extraction of Gleason Score for prostate cancers and Breslow thickness for melanomas.

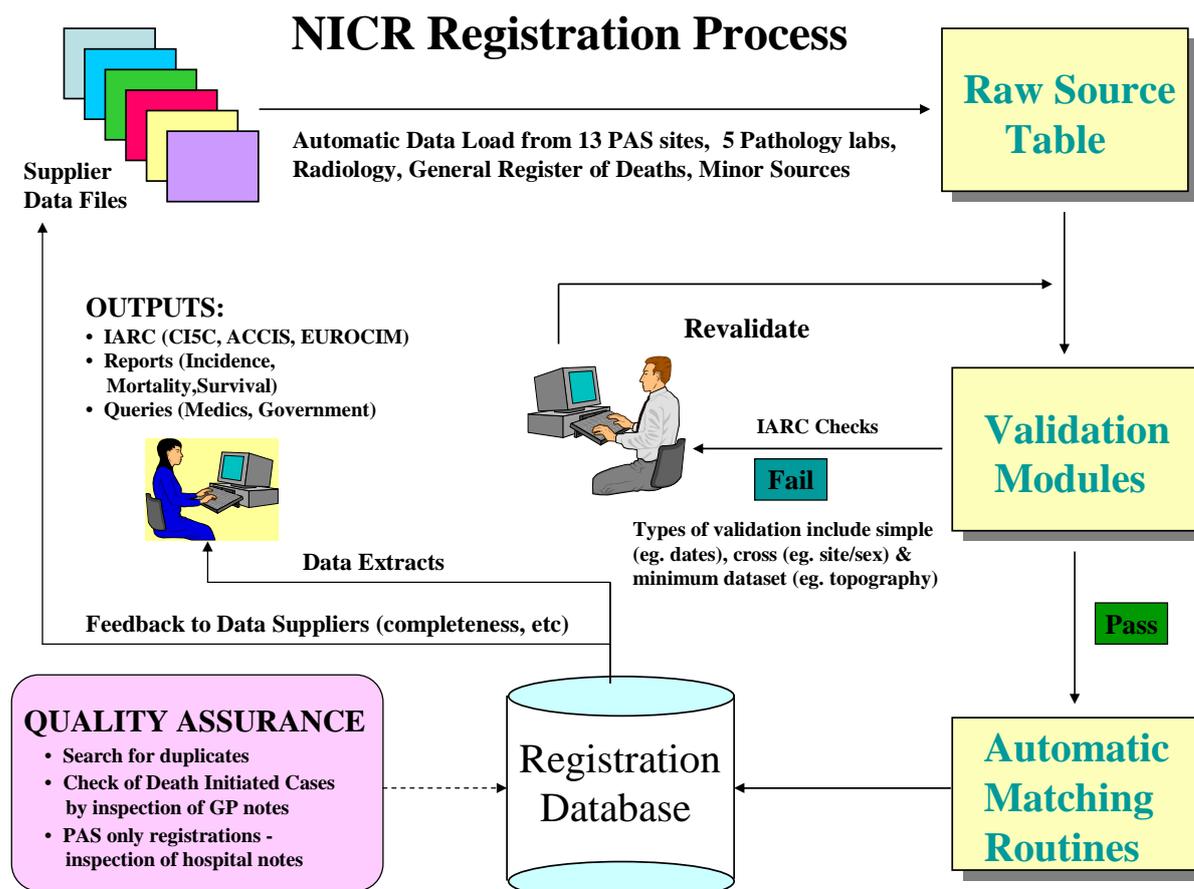
From the Patient Administration System (PAS) the Registry obtains demographic information on individual patients, along with data on their length of stay in the hospital and basic tumour information such as the site and behaviour of the tumour as an ICD-10 code. The PAS information includes limited treatment information on surgical procedures.

Northern Ireland Cancer Registry

Main Data Sources & Outputs



| | | |
|--|---|--|
| <ol style="list-style-type: none"> 1. Peer Reviewed research Publications (approx. 32). 2. Input to Undergraduate curriculum at QUB and Post Graduate Oncology courses. 3. Regular Information to local media. 4. Close involvement with DHSSPS and NICaN in monitoring cancer services and policy development. 5. Strong links with local clinicians. 6. Advice to local charities and Patient Advocacy Groups. 7. Input to N. Ireland Action on Smoking and Health Committee. 8. Input to N. Ireland Strategic Implementation for Reduction in Skin Cancers. | <p><u>Reports</u></p> <ol style="list-style-type: none"> 1. Survival of cancer patients in Northern Ireland 1993-2004 – Report, Summary published October 2007. 2. Cancer Trends in Northern Ireland 1993-2003 – Report July 2006. 3. All Ireland Cancer Statistics Second Report 1998-2000 - Report, Summary published September 2004. 4. Cancer in Northern Ireland 1993-2001: A Comprehensive Report - Report, Summary published May 2004. 5. Investigation of Cancer Incidence in the Vicinity of Cranlome Telecommunications Mast published May 2004. 6. Survival of Cancer Patients in Northern Ireland 1993-1995 - Report, Summary published September 2001. 7. All Ireland Cancer Statistics 1994-1996 - Report, Summary published Marcy 2001. 8. Cancer Incidence in Northern Ireland 1993-1995 - Report, Summary published 1999. 9. Cancer Deaths in N. Ireland - An Analysis of Patterns and Trends published November 1995. 10. Data from NICR are included in Cancer Incidence in Five Continents | <p><u>Cancer Service Audits</u></p> <ol style="list-style-type: none"> 1. 1996/2001/2005: Upper GI published September 2007. 2. 2001/2 & 2004/5: Thyroid published September 2007 3. 1996 & 2001: Ovary & Cervix published November 2006. 4. 1996 & 2001: Pancreas published February 2006. 5. 1996 & 2001: Colorectal published October 2005. 6. 1996 & 2001: Prostate published August 2005. 7. 1996 & 2001: Lung published July 2005. 8. 1996 & 2001: Breast published May 2005. 9. 1996 & 2001: Oesophagus & Stomach published April 2005. |
|--|---|--|



5.4.4 Data Collected

The Registry collects information on all neoplasms diagnosed in Northern Ireland including non melanoma skin (NMS) cancers. In addition some cancer-related conditions such as Barrett's oesophagus, Bowen's disease, hydatidiform moles and CIN-I and CIN-II of the cervix are also recorded; also all Prostate Specific Antigen tests are collected. Annually for the main registrations the Registry processes 60,000 consultant episodes from PAS, 32,000 pathology events (histology and cytology), 3,500 cancer deaths, over 11,000 non cancer deaths and approximately 8,500 COIS registrations, to produce almost 7,000 registrations excluding NMS cancers.

A major focus of the Registry's operational work is on the verification of the information from a single death certificate (death initiated cases) or a single hospital admission. Trained registry staff examine General Practitioners' notes to verify Death Certificate Only (DCO) cases. The staff also examine hospital records for cases identified without confirmatory histopathology or cytology to verify diagnosis, dates of diagnosis, etc. Histopathology reports are also checked where there is conflicting information or other possible errors, which involves review of over 1000 hospital notes and about 500 GP records annually.

Investigations using 'data mining' techniques have resulted in electronic extraction of staging information, i.e. Gleason Scores in prostate cancer and Breslow depth for malignant melanomas from electronic pathology reports.

Security

The NICR routinely uses finger print technologies in addition to the usual security afforded by passwords, etc to access PCs and laptops. An encrypted registry database is held as back-up in local and distant bank safety deposit boxes, with intermediate storage onsite in a fireproof safe. A security document modelled on Health and Personal Social Services Information Technology

Security Policy based on ISO 17799 Standard has been developed and implemented within the Registry. The Registry has developed and rehearsed a Contingency Plan in line with QUB policy; this allows organisational planning and preparation in the event of a disaster within the Registry or its buildings.

5.4 Staging

The Registry does not currently routinely receive staging information on tumours, however it does extract some staging information from histopathology reports. At present pathological staging is carried out by Registry staff on selected tumour sites - breast, colon, rectum, cervix, melanoma, bladder, testis and ovary. An electronic tool to facilitate the clinician role in staging cancer has been developed by the Registry. Pilot studies indicate enhanced recording of stage. The Registry has piloted the capture of staging and other information at the Multidisciplinary Team meetings (MDMs), where individual patient treatment plans and care are discussed. The use of MDMs has progressed in Northern Ireland; however to date the majority of patients are not discussed at MDMs, see Table 1 below.

Table 1: Multidisciplinary Team Meetings Percentage of Patients Discussed

| Site | MDM recorded in notes | Number of Patients (%) | | |
|--------------------------------|-----------------------|------------------------|---------------------|---------------------|
| | | 1996 (n=764) | 2001 (n=881) | 2005 |
| Breast | | | | |
| | Yes | 30 (4%) | 230 (26%) | NA |
| | No | 734 (96%) | 651 (74%) | NA |
| Ovary | | 1996 | 2001 (n=146) | 2005 |
| | Yes | NA | 58 (40%) | NA |
| | No | NA | 88 (60%) | NA |
| Colon & RS Junction | | 1996 (n=524) | 2001 (602) | 2005 |
| | Yes | 1 (<1%) | 107 (18%) | NA |
| | No | 523 (99%) | 495 (82%) | NA |
| Rectum | | 1996 (n=190) | 2001 (n=203) | 2005 |
| | Yes | 1 (<1%) | 62 (31%) | NA |
| | No | 189 (99%) | 141 (69%) | NA |
| Oesophagus | | 1996 (n=200) | 2001 (n=214) | 2005 (n=198) |
| | Yes | 2 (1%) | 68 (32%) | 120 (61%) |
| | No | 198 (99%) | 146 (68%) | 78 (39%) |
| Stomach | | 1996 (n=179) | 2001 (n=176) | 2005 (n=139) |
| | Yes | 4 (2%) | 28 (16%) | 58 (42%) |
| | No | 175 (98%) | 148 (84%) | 81 (58%) |

NA = not available

Source: Northern Ireland Cancer Registry Audit Reports

5.5 Links with external units to facilitate data capture

Registry staff are working with members of the Service Delivery Unit, a department of DHSSPS, to enable the capture of cancer waiting times data which was not collected in N. Ireland prior to July 2007 and becomes mandatory in 2008. Registry staff have developed an electronic multidisciplinary team management system which can also facilitate Trusts to collect cancer waiting times data and other data items including stage which should then be available to the Registry.

The Registry has also worked with the local cancer network, NICaN, in the development of tumour specific datasets to facilitate the MDM process. These clinical databases not only enable the recording of tumour-specific data required by minimum datasets, and data required for national audits but also the outcome of multidisciplinary management decisions. To date systems for haematology, oesophageal, stomach, lung, colorectal, breast, brain, gynaecology, urology and head and neck cancer have been developed.

These developments are part of our ongoing active role in pursuing new and more timely data sources for the N. Ireland Cancer Registry.

5.6 Data Quality

Data Quality is enhanced by the following process:

Identification of New Patients

The Registry receives data electronically and therefore focuses a lot of resources on Quality Control and Quality Assurance of the data, as opposed to data collection. Currently patients are identified by their name, date of birth, address, disease, etc. Northern Ireland does not use the NHS number but uses a Health and Care Number (HCN). This number is received on Registry extracts from Trusts via the Directorate of Information Services (DIS); however, only a few of the Trusts had implemented use of the HCN by December 2006. A second unique identifier is the Community Health Index number (CHI). The NICR has been working closely with the Central Services Agency (CSA) to improve the completeness of this number on the database (completeness has risen from less than 30% to 80% as a result of this work).

Checking for Errors

TVO staff check electronically recorded pathology data and, if necessary, check hospital or GP records to address potential errors and to clarify conflicting information by manual resolution.

Table 2: Numbers of patient records examined by NICR staff

| Year | Hospital Records | GP Records |
|------|--|------------|
| 1993 | 10,500 for three years (excluding in situ, benign & uncertain behaviour) | 945 |
| 1994 | | 689 |
| 1995 | | 656 |
| 1996 | 4,823 (including in situ, benign uncertain behaviour) | 678 |
| 1997 | 3,290 (excluding in situ, benign uncertain behaviour) | 711 |
| 1998 | 3,435 (excluding in situ, benign uncertain behaviour) | 511 |
| 1999 | 3,798 (excluding in situ, benign uncertain behaviour) | 567 |
| 2000 | 1,193 (excluding in situ, benign uncertain behaviour) | 329 |
| 2001 | 769* (excluding in situ, benign uncertain behaviour) | 332 |
| 2002 | 1,504 (excluding in situ, benign uncertain behaviour) | 423 |
| 2003 | 2,396 (excluding in situ, benign uncertain behaviour) | 437 |
| 2004 | 1,422 (excluding in situ, benign uncertain behaviour) | 421 |
| 2005 | 1,041 (excluding in situ, benign uncertain behaviour) | 585 |

* In 2001 a major audit project involved examination of an extra 4,500 hospital notes, therefore the number of 'PAS only' cases requiring inspection was lower. (A similar note re-abstraction

study for patients diagnosed with cancer in 2006 is planned for 2007). Notes from 2003 were found to be more problematic; more needed to be checked to ensure quality.

Investigation of unexpected survivorship

Follow up of long term survivors for cancers with poor outcomes (e.g. lung cancer) highlighted a problem of non cancers having been diagnosed as cancer in a small proportion of cases. There were 'PAS only' cases for which medical records were not available for checking cases where the only information is from hospital discharge. The Registry documented these for 1993-1999 (n=781) and contacted GPs to confirm diagnosis. This questionnaire survey had an 87% response rate and was successful in eliminating 207 non-malignant or prevalent tumours - 0.5% of the database (30 tumours per year). This exercise will be repeated in 2007.

Using Central Services Agency

The accuracy of data is further enhanced by the use of a matching service provided by the Central Services Agency to validate and improve postcode allocation, community health index (CHI) - ultimately Health and Social Care Numbers, and records with date of death (available from the General Registrar's office, but not in a timely manner); this now takes place annually.

Audits

The Cancer Services Audit Project, organised by the NICR, has provided useful information regarding data quality; the audit refers to notes for all cases of breast, lung, ovary, cervix, oesophagus, stomach, colon, rectum, ovary, cervix and prostate cancer were reviewed for 1996 and 2001 and pancreatic cancer (2001 only) thyroid (2001/2002 and 2004/2005). Further audits on patients diagnosed in 2005/2006 are ongoing.

Utilisation of data held by local GPs

The 2004 GP Contract (Terms and Conditions of service) requires GPs to hold registers of patients with chronic diseases, including cancer. The NICR offered all GPs in Northern Ireland the opportunity to receive a list of their cancer patients, as held by the NICR in 2004. This provided the facility for GPs to set up a register of their cancer patients and has also served as a check to return an updated list of patients. This exercise demonstrated a high degree of accuracy and completeness of the NICR data and a repeat exercise is planned in 2008.

Note Review

A note review was conducted on a 5% random sample of registrations from 2002 as part of the Quality Assurance programme for the Registry. The re-abstraction is complete and has shown a high degree of accuracy for 'site', 'date of diagnosis' and 'morphology' of the tumour. The process has been completed for 2003 data and will be repeated for 2004 data.

5.7 Use of the data

The Registry not only registers all cancers in the region, but also provides a cancer information service and has close connections with the Breast and Cervical Screening Services and the Cancer Network. Information supplied by the Registry is routinely used by policymakers to evaluate and plan cancer services throughout the region. Registry reports on cancer survival, trends, cluster investigation and disease-specific audits are available at www.qub.ac.uk/nicr. The Registry's unique data on Barrett's oesophagus, adenomatous polyps of the colon and Prostate Specific Antigen have formed the basis of major, externally funded research projects.

Research

- The international links afforded by the US National Cancer Institute / Ireland / Northern Ireland Consortium has enhanced opportunities for collaborative research. This has included the hosting of international cancer conferences on the Island of Ireland, the most recent was

facilitated by the NICR and received 360 delegates and more than 60 speakers; the conference was held over three days with parallel sessions.

- The Registry has forged close collaborative links within Queen's University Belfast, which has enabled the NICR to partake in international research, despite having been established for only fourteen years. Examples of this are (i) Barrett's Oesophagus and the risk of oesophageal cancers (ii) factors in the use of PSA testing and the implications of a raised PSA in predicting prostate cancer (iii) an international case control study of risk factors for pancreatic cancer.

The Registry has produced 13 reports (2004–2007) including the second All Ireland report and 19 peer reviewed publications (2004-2007). See Appendix for details.

5.8 International Links

- The NICR is the UK Lead Registry for two major European Cancer Projects; EURO CARE (International comparisons of cancer survival) and EUROCHIP (a multi-centre project examining the potential for improving information on cancer).
- The Registry has close links with the National Cancer Registry of Ireland, under the umbrella of the Northern Ireland / Ireland / USA National Cancer Institute Consortium. This has resulted in several joint All Ireland research programmes, which have received external peer reviewed funding.
- The Northern Ireland / Ireland / NCI Consortium has provided increased opportunities for training. Staff from the NICR have availed of the following training opportunities at NCI.
 - 4/5 week course Summer Curriculum in Cancer Prevention – attended by 3 staff members
 - Cancer Epidemiology/Prevention Fellowships at NCI – 3 Registry affiliated research staff
- The Registry has recently established links with the International Association for Research on Cancer (IARC) with a view to pursuing work on skin, prostate and breast cancers.
- The Registry has compared rates of cervical cancer with Estonia and, as a result, is pursuing the possibility of securing funding to undertake a comparative study of HPV prevalence.
- A case control study of pancreatic cancer is being expanded to include several European countries
- Barrett's research now includes partners in USA, UK and Europe

5.9 Staff Training

Training needs are identified via annual staff appraisals

- Registry staff receive an induction programme followed by mentored training for variable periods depending on need. Tumour Verification Officers also have training based on the UKACR Training Manual; topics include - Registration Principles, Data Abstraction, Basic Tumour Biology, Site Specific Detection, Classification, Treatment and Staging.
- As part of Queen's University Belfast, staff have access to all training events and have taken part in various computer courses, media training, report writing, statistical training, etc.
- Staff have also participated in Statistical Methods Training provided by the Clinical Research Support Centre located in the Royal Victoria Hospital.
- Five Tumour Verification staff have successfully completed the ECDL course.
- Staff have attended UKACR training events and survival analysis courses.
- Three staff have attended the National Cancer Institute Summer School in Cancer Prevention.

5.10 Research Outputs

The Registry, as part of the University, has facilitated the development of research based on the Registry held data. Currently there are seven ongoing studentships / fellowships and four completed PhDs/MDs. The Registry has close links with the University's Cancer Epidemiology and Prevention Research Group and is supporting ten research projects.

6 REVIEW REPORTS

6.1 Organisation and Management

Summary of Compliance

| Northern Ireland Cancer Registry | 1* | | 1 & 2 | |
|---|-------|-------------|-------|---|
| Topic 4A – Organisation and Management | 12/12 | 100% | 0/0 | - |

General Profile

The Review Team was impressed by the remarkable achievements made by the Northern Ireland Cancer Registry (NICR) since its inception 13 years ago. Over that time it has established an active cancer intelligence service, which is firmly embedded in health service provision in Northern Ireland. The work of the Registry is considered by planners and providers of cancer services to be of pivotal importance.

The Registry revolves around the commitment, leadership and energy of the Director, who has been involved since its formation. A well organised structure has evolved in combination with support from the DHSSPS and QUB. This structure enables the production of high quality intelligence that is both relevant to the local community and at national level; a view endorsed by the Chief Medical Officer present at the review meeting.

The Review Team commends the Registry for delivering an excellent, well-rounded and integrated cancer intelligence function, making a real difference to the delivery of patient care, and acting as a support and catalyst to clinicians, charities and decision makers. The NICR is clearly a critical cog in the machinery striving to reduce the burden of cancer and improve outcomes for patients in Northern Ireland.

The lack of a clear legal framework for the NICR remains a concern in that, unlike English registries, NICR's activities are not covered by the provisions of Section 60 of the Health and Social Care Act (2001) and by the remit of the Patient Information Advisory Group (PIAG). In addition, agreed UKACR policies are applicable to the NICR, but because these UKACR policies currently make reference to PIAG and Section 60, their interpretation and application in Northern Ireland are not straightforward. This may leave the NICR vulnerable to legal challenges regarding its use of patient identifiable information.

Links between the Steering Group and the Council are clear and are seen to work effectively. Good governance processes, both financial and managerial, are in place with both the DHSSPS and Queen's University Belfast.

Funding for the Registry comprises a mix of "core" and "project" funding; the organisation has worked hard and efficiently to secure additional funding from several sources.

The Registry is closely involved in the definition and development of the "patient tracker" role in the wider health community, and is providing training to staff external to the organisation using the UKACR Training Manual.

The NICR operates its registration processes effectively using a wide range of local electronic data and national electronic sources, including hospital PAS systems, pathology, national registers and primary care. The Registry has played an important role in the establishment and checking of primary care cancer registers in keeping with the requirements of the GP contract. The Registry produces a regular newsletter that is widely disseminated and also has a clear policy for resolution of problems with stakeholders.

Immediate Risks

None

Concerns

- The lack of a clear legal framework is a concern and options for resolution of the difficulties should be explored.

Further Considerations

- Consideration should be given to include within the core funding of the organisation the established work programmes that have resulted from innovative projects undertaken by the NICR. Examples for future funding would be the routine production of audit reports, the continuing development of database links to MDTs and the training of staff external to the Registry.
- It would be valuable for the UKACR to review the existing UK wide policies with a view to ensuring their relevance and ease of application across all cancer registries.

Good Practice

- The high level of stakeholder engagement, demonstrated by
 - close involvement in specification, development and training and support of the “patient tracker” role
 - cross-verification between GP chronic disease registers with data held by the Registry
 - extensive patient and user involvement.
- The proactive approach to disseminate work and results into the public domain, as illustrated by the good relationships with the media, and the provision of reports in public libraries.
- There was evidence of strong governance arrangements, financial and managerial, exemplified by the close working relationship with the Chief Medical Officer and others in the DHSSPS, as well as in the clear and well established proactive approach to securing additional funding.
- The innovative job title of TVOs, which not only accurately describes the work done, but also bestows professional status to these team members.

6.2 Uses of Information

Summary of Compliance

| Northern Ireland Cancer Registry | 1* | | 1 & 2 | |
|---------------------------------------|-----|-------------|-------|-------------|
| Topic 4B – Uses of Information | 6/6 | 100% | 1/1 | 100% |

General Profile

The range of outputs produced by the NICR is impressive and includes a series of audit reports, incidence and survival reports, and peer reviewed publications. At the same time the Registry has been very successful in securing funding from a range of sources to support the development of audits, scientific studies and other peer reviewed reports; these activities clearly represent a significant investment of energy, time and organisation.

The NICR has made very good use of its position in the University to develop collaborative research, and has built up links with international bodies, including the National Cancer Institute in the United States of America and International Agency for Research on Cancer in Europe. The Registry has also found opportunities for individual staff members to benefit from training in epidemiological and statistical methods, which has been delivered in major centres abroad.

Close collaboration with clinicians has enabled the production of clinically relevant audit reports, which has resulted in changes in clinical practice with benefit to patients. The Registry is to be commended for pursuing the publication of this work despite initial reluctance from some clinicians, to the extent that the Registry is now being asked by clinicians to conduct follow-up audits to document the changes in practice and patient outcomes.

The Review Team was impressed by the high profile achieved by the NICR within the health community, and the usefulness of their outputs to inform improvements in care is stimulating greater interest and demands on available resources. However, there is potential for the growing information and intelligence requirement to begin to outstrip the current capacity to deliver.

The process by which the Registry manages its genetic requests, using a specialist nurse for management of local requests, is seen as both practical and effective and enhances further strengthening of clinical links. However, the Review Team considered that the local requests should be identified and included in the overall total workload when monitoring the responses to genetic questions.

The NICR is justifiably proud of its website, which contains comprehensive and detailed data and reports. The incidental evidence of a decreasing trend in the number of data requests to the NICR in recent years suggests that users may be accessing data on the website more frequently as a means of obtaining information.

Immediate Risks

None

Concerns

None

Further Considerations

- It would be beneficial to explore options for inclusion in the team of some or all of the additional skills that were identified to support ongoing work; these include skills and capacity in statistics, public health, administration, clinical liaison and publication management

Good Practice

- The quality of engagement with clinicians and integration with the wider health community; there was evidence of a holistic approach to engagement with services.
- The use of TVOs to consolidate audit and quality assurance by reference to medical case notes.
- The use of a specialist nurse to manage all local genetic requests.
- The audit reports are received well and are clearly relevant, thus positively influencing change in local practice.
- Academic liaison is influential in securing grants and in progressing publications and research fellowships

6.3 Data Quality

Summary of compliance

| Northern Ireland Cancer Registry | 1* | | 1 & 2 | |
|----------------------------------|-------|------------|-------|---|
| Topic 4C – Data Quality | 13/16 | 81% | 0/0 | - |

General Profile

The Registry is actively engaged in negotiations with suppliers of key data sources. Delays in receipt of annual death certificate data are currently being mitigated by use of quarterly updates from the CSA, but this poses additional cost implications. In addition, to manage the potential risk of record duplication due to the lack of coverage of the Unique Healthcare Identifier and post code, the Registry uses the master patient index to verify data such as addresses, postcode and identification of a patient's General Practitioner and to update registry records.

There was evidence of a comprehensive Quality Assurance system in place, with excellent use of automation to support the process, followed by tumour specific and clinical validation.

It was noted that the relatively small population numbers applicable to the Registry may result in spurious random variations in attainment against UKACR performance indicators. The Review Team acknowledged however that new data flowing from MDTs will enhance performance against indicators. The Review Team also noted the excellent practice of feeding back of quality controlled data to the suppliers of the data.

There was evidence of excellent use of the UKACR Training Manual for training staff, both internal and external to the organisation; for example it is used in training for TVOs, MDT co-ordinators, statisticians and IT staff.

Immediate Risks

None

Concerns

None

Further Considerations

- The Registry is commended on the report showing the variations in data flows from their sources, but more regular reviews of notifications and registrations throughout the year may be beneficial, especially with the anticipated increase of data that will flow from the MDTs.

Good Practice

- The use of the UKACR Training Manual by a broad range of staff both within, and external to, the organisation.

6.4 Data Sources and Processing

Summary of compliance

| Northern Ireland Cancer Registry | 1* | | 1 & 2 | |
|---|-----|-----|-------|---|
| Topic 4D – Data Sources and Processing | 5/7 | 71% | 0/0 | - |

General Profile

There is an excellent track record of communication between the Registry and the screening services to monitor patient screening histories since the Registry's inception. Regrettably, this enviable position with regard to cervical screening has deteriorated recently, owing to changes in external IT systems and organisations, which has been outside the control of the Registry. These changes have resulted in a situation whereby the Cervical Screening Quality Assurance Reference Centre (QARC) no longer has access to screening histories before 2005, which limits the ability of the Registry to assist the QARC with audit of cervical cancers. The QARC is trying to resolve this through negotiation with the Department of Information Systems (DIS), who controls access to this historical data.

The extraction of Gleason score and Breslow depth (prognostic indicators for prostate and melanoma skin cancers respectively) from pathology reports has been quality assured and has been successfully implemented within the NICR. However, it is noted that for the system to be universally applicable there would need to be locally applied comparisons with the pathology service prior to implementation to ensure the relevance and accuracy of extractions.

The Review Team noted that the NICR does not currently have access to chemotherapy data held on the COIS.

Registry staff reported some occasional difficulties in accessing medical records for validation purposes and that the need for such access may increase with the development of new electronic data feeds from new sources, such as those from the MDT databases. The Review Team suggested that the NICR may benefit from renegotiating Service Level Agreements with relevant organisations (either directly with hospitals or via commissioners) in which the process for provision of access to medical records is made explicit.

The imminent introduction of the MDT forms and databases will require data transfer from hospitals to the Registry, which will provide an opportunity to review the broader issues around access to data between and across the organisations. This could provide an opportunity to enhance and make more robust the SLAs in place concerning data transfer and access by Registry staff to data held in hospitals.

A patient representative attending this session commented on the wide use of acronyms in the discussion and the documentation. The Review team acknowledged the need to avoid this and suggested that the Coordinating Team address this in future peer reviews.

Immediate Risks

None

Concerns

- It was of concern to all present that the Cervical QARC does not retain access to the full and historic database containing screening history before 2005; these data are now held by an agency within the DHSSPS. The Review Team considered that re-population of the complete cervical screening data set within the QARC should be a priority. It would be beneficial to all parties for the cervical screening records to be complete and accessible; it is also important to ensure that the new data set dating from the recent re-organisation is complete.

Further Considerations

- There would be value in formalisation and standardisation of the routine checking of QARC data versus Registry data.
- The Registry should review the usage of COIS by other stakeholders to better understand how these users have dealt with extraction of data for Cancer Registry purposes.
- The Registry might consider it beneficial to design and renegotiate SLAs to improve access to trust held data and to facilitate ease of access to the data.

Good Practice

- The electronic derivation of staging information and the Quality Assurance process in place to validate the scores.
- Proactive and innovative use of electronic data and sources, exemplified by the development of electronic database tools, including the tumour-staging tool and the databases for MDTs.

7 GLOSSARY OF TERMS AND ABBREVIATIONS

7.1 Generic Terms

| | |
|--------------------------|---|
| Cancer Registries | Collect information on what cancers occur, how advanced they are and where they are diagnosed and where and by whom treated. The availability of information may be variable at different cancer registries, depending on local practices and the completeness of the reporting of staging information by clinicians. |
| CMO | Chief Medical Officer |
| CQuINS | The Cancer Quality Improvement Network System; a web based database used to support the Peer Review process |
| Data set | A standard set of data items, concepts and definitions to enable the production of national and nationally comparable information. Minimum dataset is the minimum nationally acceptable configuration of these components. |
| DCO | Death certificate only – a registration for which the only information available to the registry is that on the death certificate |
| IT | Information technology |
| Malignant | Tumour that is invasive and destroys the tissue in which it originates. A tumour that will metastasise. In more general terms, tending to cause death, disposed to do harm. |
| NCRAG | National Cancer Registration Advisory Committee |
| NCRC | National Cancer Registry Coordinator for England |
| NHS | National Health Service |
| NICE | National Institute for Clinical Excellence |
| ONS | Office for National Statistics |
| PCT | Primary Care Trust –Group of GPs, nurses and other health professionals working together to: Improve health; Develop and provide primary and community services; Commission secondary care services. |
| PHIT | Public Health Intelligence – information about public health issues, with interpretation |
| PIs | Performance Indicators |
| PSA | Prostate specific antigen - a marker for prostate cancer |
| QA | Quality Assurance |
| RDPH | Regional Director of Public Health |
| SHA(s) | Strategic Health Authority(ies) |
| UKACR | United Kingdom Association of Cancer Registries |
| Cancer Registries | Collect information on what cancers occur, how advanced they are and where they are diagnosed and where and by whom treated. The availability of information may be variable at different cancer registries, depending on local practices and the completeness of the reporting of staging information by clinicians. |
| CIS | Cancer Information System |

| | |
|------------------|--|
| ClearNet | The NHS-wide Clearing Service which provides a means of exchanging and processing high volumes of data between NHS user organisations |
| CMO | Chief Medical Officer |
| CQuINS | The Cancer Quality Improvement Network System; a web based database used to support the Peer Review process |
| Data set | A standard set of data items, concepts and definitions to enable the production of national and nationally comparable information. Minimum dataset is the minimum nationally acceptable configuration of these components. |
| DCO | Death certificate only – a registration for which the only information available to the registry is that on the death certificate |
| DH | Department of Health |
| DTI | Department of Trade and Industry |
| GO | Government Office – local authority administrative area, increasingly coterminous with NHS areas |
| HCC | Healthcare Commission - National body authorised by parliament to regulate healthcare in both public and private sectors. The NHS Cancer Peer Review Programme works in partnership with the HC. |
| HES | Hospital Episode Statistics – a database of all admission and day care episodes in hospitals in England |
| IT | Information technology |
| Malignant | Tumour that is invasive and destroys the tissue in which it originates. A tumour that will metastasise. In more general terms, tending to cause death, disposed to do harm. |
| NCIC | National Cancer Intelligence Centre – unit within the ONS collating and analysing national cancer registration data |
| NCRAG | National Cancer Registration Advisory Committee |
| NCRC | National Cancer Registry Coordinator for England |
| NHS | National Health Service |
| NICE | National Institute for Clinical Excellence |
| NLOs | Network Liaison Officers |
| NSTS | National Strategic Tracing Service – master index of details of residents in England |
| NWCS | NHS Wide Clearing Service – see ClearNet |
| ONS | Office for National Statistics |
| PCT | Primary Care Trust –Group of GPs, nurses and other health professionals working together to: Improve health; Develop and provide primary and community services; Commission secondary care services. |
| PHIT | Public Health Intelligence – information about public health issues, with interpretation |
| PIs | Performance Indicators |
| PSA | Prostate specific antigen - a marker for prostate cancer |

| | |
|--------|---|
| QA | Quality Assurance |
| RDPH | Regional Director of Public Health |
| SHA(s) | Strategic Health Authority(ies) |
| UKACR | United Kingdom Association of Cancer Registries |

7.2 NiCR Specific Terms

| | |
|----------|---|
| ACCIS | Automated Childhood Cancer Information System - a system of provision, presentation and interpretation of data on cancer incidence and survival of children and adolescents in Europe (developed at IARC for the European Network of Cancer Registries) |
| CHI | Community Health Index number |
| CI5C | Cancer Incidence in Five Continents (a series published by IARC) |
| COIS | Clinical Oncology Information System |
| CSA | Central Services Agency |
| DHSSPS | Department of Health, Social Services and Public Safety |
| DIS | Directorate of Information Services |
| ECDL | European Computer Driving Licence |
| EUROCARE | European cancer registries study on cancer patients' survival and care |
| EUROCHIP | European Cancer Health Indicator Project - it focuses on fighting inequalities in cancer. |
| EUROCIM | A database of cancer incidence and mortality in European registries, with powerful statistical software for its analysis (developed at IARC for the European Network of Cancer Registries) |
| HCN | Health and Care Number |
| HPV | Human Papilloma Virus - persistent infection with "high-risk" types of HPV is the main risk factor for cervical cancer. |
| IARC | International Agency for Research on Cancer |
| MDM | Multidisciplinary Team meetings |
| MDT | Multidisciplinary Team |
| NICR | Northern Ireland Cancer Registry |
| NISRA | Northern Ireland Statistics and Research Agency |
| PAS | Patient Administration System |
| PIAG | Patient Information Advisory Group – it provides advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001 (in England). |
| QARC | Quality Assurance Reference Centres for cancer screening programmes |

| | |
|-----------------|--|
| QUB | Queen's University Belfast |
| SLA | Service level agreement |
| TVO | Tumour Verification Officer |
| CCRIS-2 | Bespoke cancer registration software used by NYCRIS until 2006 |
| CfH | Connecting for Health |
| CRUK | Cancer Research UK |
| CWT | Cancer Waiting Times |
| EUROCARE | Project using data from members of the European Network of Cancer Registries to provide comparative analyses of cancer site-specific survival |
| IOG | Improving Outcomes Guidance |
| LTHT | Leeds Teaching Hospitals Trust |
| NE | North East |
| NW | North West |
| NYCRIS | Northern and Yorkshire Cancer Registry & Information Service |
| PHO | Public Health Observatory |
| PRAXIS | The Registry software developed by Thames Cancer Registry and used by TCR |
| PROTECT | Prostate testing for cancer and treatment - a research project aiming to evaluate treatments for localised prostate cancer. |
| QARC | Quality Assurance Reference Centre |
| RES | Radiotherapy Episode Statistics - a database of radiotherapy episodes in hospitals in England |
| SMT | Senior Management Team |
| SUS | Secondary Uses Services - The single NHS-wide system for processing Commissioning Data Sets which replaced the NHS-Wide Clearing Service on 31 December 2006 |
| Y&H | Yorkshire and Humber |
| WTE | Whole Time Equivalent |

Cancer Peer Review Report Northern Ireland Cancer Registry

Cancer Registries Peer Review Team January 2008

