National Cancer Registry annual report and accounts for year ending 31 December 2013

National Cancer Registry

Annual report and accounts for year ending 31 December 2013

National Cancer Registry Ireland

National
Cancer
Registry
Ireland

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NATIONAL CANCER REGISTRY

ANNUAL REPORT AND ACCOUNTS

FOR THE YEAR ENDING 31ST DECEMBER 2013

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Ireland

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National Cancer Registry Ireland

FOREWORD

As Chair of the Board of the National Cancer Registry of Ireland, it gives me great pleasure to report on the progress the NCRI has made this year in developing a new Strategic Plan, implementing a new website, involving integration of electronic capture of cancer treatment data across the spectrum of HSE services and the private sector. The NCRI's research portfolio and publications are also exemplary and both the analysis of cancer specific incidence, mortality and quality, and the Registry's international collaborations, are continuing to grow and develop in an exemplary way. The evolution of improved information and technology within the healthcare sector will further facilitate the timeliness and efficiency of acquiring information, and thus the NCRI will continue to provide optimal planning information for national screening programmes, prevention, diagnoses, treatment and survivorship nationally.

The members of the Board would like to thank Dr Harry Comber for his leadership over the last twenty years and to express our appreciation of the comprehensiveness and quality of the National Cancer Registry.

Dr. Susan O'Reilly MB, BCh, BAO, FRCPC, FRCPI
National Director
National Cancer Control Programme

National Cancer Registry Ireland

DIRECTOR'S STATEMENT

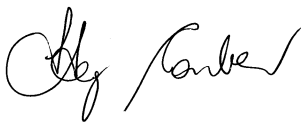
With the appointment of a Board for a three-year term, 2013-2016, our attention has focussed on strategic planning. The Board has agreed a comprehensive medium–term strategy and we are exploring the optimum ways in which to deliver on this. Greater emphasis will be placed on the involvement of the clinical community, as both providers and users of our data. We look forward to the development of cancer information plans at hospital levels, which will integrate with, and enhance, the operations of the National Cancer Registry. Already such a plan is being developed, in consultation with the Registry, in the West/North-West hospital group.

The increasing availability of electronic data is also challenging us how to best access this data, and how it should be processed and integrated with our manual data collection. This will have to be done while maintaining the current level of data detail and accuracy. In common with all public agencies, we are attempting to achieve more with fewer resources, and the willingness of our staff to work within these resource limitations has been crucial to continuing registration. The number of registrations continues to increase by about 5% annually, while the number of staff remains fixed.

Our research programme is based on both registration data and on other data sources. Productivity has increased from 18 peer-reviewed publications in 2012 to 30 in 2013. Dissemination has also been enhanced by the development of a new website, giving easy access to all Registry publications and online access to up-to-date survival data. Engagement with the public has been facilitated through a Twitter account.

Our collaboration with our nearest neighbours has been strengthened by the establishment of the UK and Ireland Association of Cancer Registries (UKIACR), which seeks to enhance cooperation among the cancer registries on the two islands in registration, research and policy support.

The long-term future of the National Cancer Registry Board remains unclear, but we hope that the Registry, no matter what framework will eventually contain it, will continue to function as effectively and independently as in the past.



Harry Comber

National Cancer Registry Ireland

HISTORY AND BACKGROUND

ESTABLISHMENT

The National Cancer Registry Board was established by Statutory Order 19 of 1991, *"The National Cancer Registry Board (Establishment) Order"* under the *Health (Corporate Bodies) Act, 1961.* The Board discharges all its statutory responsibilities through the National Cancer Registry. The Order was amended twice; in 1996 by S.I. No. 293/1996 (*The National Cancer Registry Board (Establishment) Order, 1991 (Amendment) Order*) and in 2009 by the *Health (Miscellaneous Provisions) Act 2009*.

The Minister for Health and Children, Mary Harney, T.D. on 15th October 2008 announced that the National Cancer Registry would be integrated into the Health Service Executive in 2010. This was confirmed by the Minister for Finance in his 2009 Budget speech. However, this has been deferred pending the establishment of new health structures and the enactment of the Health Information Bill.

THE NATIONAL CANCER REGISTRY BOARD

The National Cancer Registry Board is a statutory body established in 1991 under the National Cancer Registry Board (Establishment) Order as an agency of the Department of Health and Children (as it was at the time). The Board has a full membership of seven who are appointed by the Minister for Health.

The current Board was appointed by the Minister on February 15th 2013 for a term of three years. Its members are:

- Dr Susan O'Reilly (Chair)
- Mr Michael Conroy (appointed 14 October 2013)
- Ms Orla Dolan (appointed 14 October 2013)
- Dr Anna Gavin
- Dr Fenton Howell
- Ms Mary Jackson (resigned 13 October 2013)
- Mr John McCormack.

STATUTORY FUNCTIONS

The statutory functions of the National Cancer Registry Board, as set out in Statutory Order 19 of 1991, are:

- to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland;
- to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs;
- to promote and facilitate the use of the data thus collected in approved research projects and in the planning and management of services;
- 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.

National Cancer Registry Ireland

REPORT OF THE BOARD ON CORPORATE GOVERNANCE

Report of the Chairperson, National Cancer Registry Board for year ending 31/12/2013

1. Commercially significant developments affecting the body

   No commercially significant developments occurred during 2013.

2. Procedures for financial reporting, internal audit, travel, procurement and asset disposals:

   These are all being carried out according to official policies and guidelines.

3. System of internal financial control

   a) The Board is responsible for the body's system of internal financial control.

   b) Such a system can provide only reasonable, and not absolute, assurance against material error.

   c) Key procedures which have been put in place by the Board to provide effective internal financial control include:

   (i) A clearly defined management structure.

   (ii) A risk register was compiled in 2010 and was updated throughout 2013.

   (iii) A procedures document setting out instructions for all areas of financial activity was in place for 2013. This outlined the procedures for the administration of salaries, invoices and expense claims, use of the credit card and petty cash transactions as well as procedures for procurement and for the disposal of assets. The payroll functions were carried out by University College Cork in 2013. There were regular reconciliations carried out between National Cancer Registry Board records and those maintained by University College Cork.

   (iv) The Audit Committee was appointed by the Board on 2nd April 2013.

   (v) An ITT for Internal Audit Services was undertaken in November 2010 and a full three-year cycle of internal audits covering core financial, organisational and operational areas have been agreed by the Audit Committee and the Board. Formal internal audits were carried out in 2013 in the areas of procurement, corporate governance and information security. Internal auditors for 2013-2016 were appointed in December 2013 and a schedule of internal audits has been agreed between the internal auditors and the Audit Committee.

   (vi) An overall annual budget for the National Cancer Registry was agreed which incorporated a separate budget for IT. A report is prepared on a monthly basis to compare actual with budget figures and overall annual expected figures are updated throughout the year.

   (vii) Review by the Board at each of its meetings of periodic and annual financial reports.

d) *The Board carried out a review of the effectiveness of internal financial controls for 2013 at its meeting in March 2014.*

4. Codes of business conduct for directors and employees have been put in place and are being adhered to.
5. Government policy on the pay of the Director and all State body employees is being complied with.
6. Compliance with Government guidelines on the payment of directors' fees is not relevant as there are no directors' fees paid at the National Cancer Registry.
7. The Guidelines for the Appraisal and Management of Capital Expenditure Proposals in the public sector are being complied with.
8. Government travel policy requirements are being complied with in all respects.
9. The Code of Practice for the Governance of State Bodies (2009) has been adopted by the Board and is being fully complied with.
10. The National Cancer Registry Board complied with all aspects of contractual agreements that could have a material effect on the financial statements in the event of non-compliance. There have been no communications concerning non-compliance with requirements of regulatory or tax authorities with respect to any matter. The National Cancer Registry Board is not aware of any actual or possible non-compliance with laws or regulations that could impact on the financial statements.

Signed

Dr Susan O'Reilly

National Cancer Registry Ireland

REPORT ON SYSTEM OF INTERNAL FINANCIAL CONTROL

Governance

Board

The NCRB addresses the majority of the matters outlined in the schedule of matters, as per the Code of Practice.

Briefing for new Board members

On their appointment new members were provided with the information as in the Governance framework for the National Cancer Registry Board.

Disclosure of interests by Board members

The register of interests is maintained by the Administrator and each year Board members and all relevant staff are circulated with a request to bring their disclosure of interests up to date.

Audit Committee

The Audit Committee was appointed by the incoming Board in April 2013. It met four times in 2013.

Internal audit function

An internal audit service is in place and is carrying out a systematic audit of all areas of Registry activity. In 2013, the following areas were audited:

- Procurement
- Information security
- Corporate governance

Code of business conduct for Board members and staff

This has been updated in line with the recommendations of the internal auditors.

Procurement

All staff involved in procurement have been made aware of the Public Procurement Guidelines and directed to the www.etenders.gov.ie website for further guidance. This direction is contained within the Governance framework for the NCRB.
Guidance for staff on procurement processes has been written and circulated to all staff involved in procurement.

Tax clearance

Tax clearance procedures have been updated
The NCRB has ensured that it holds on file an up to date tax clearance certificate for all suppliers that exceed the €10,000 per annum threshold.

Disposal of assets

No assets worth more than €150,000 were disposed of during the period reviewed.

Disposal of assets to Board members/staff

All assets disposed of to Board members or staff were at a fair market-related price.
All disposals have been documented accordingly and made in accordance with appropriate procedures.

Acquisitions/Subsidiaries

NCRB has not established or acquired any subsidiaries.

Diversification of core business

There has been no requirement for diversification of NCRB's core business.

Investment appraisal

There has been no significant capital investment.

Director's remuneration

The Director's remuneration accords to appropriate guidelines and is disclosed in the Annual Report for 2013, stating annual basic salary and superannuation benefits.

Board members' fees

No fees are paid to any Board members.
Travel and subsistence payments, in line with approved rates, for the meetings that they attend are published in the annual report for 2013.

Government pay policy

All employees are paid at rates commensurate with their grade.

Reporting arrangements

The Chairperson provided a Chairperson's annual report to the Minister in March 2013. A statement regarding the system of internal control was approved by the Board and included in the report to the Minister.

Strategic and Corporate Planning

The Board adopted its most recent formal statement of strategy, for the period 2013-2016, in September 2013. A Service Plan was provided to the Department of Health in April 2013 when formal notification was received from the Department of the expenditure allocation for the year. This detailed the services planned for the year, consistent with the Board's statement of strategy, and within the constraints of the budget allocation.

Tax compliance

VAT and PSWT are accounted for by the registry. Payroll in 2013 was processed by University College Cork which provides a payroll bureau service to the Board.

Risk Management

A risk management framework document has been prepared. This sets out the definition of risk, how it is to be identified and measured, who is responsible and the infrastructure and mechanisms for monitoring and reporting on risk and mitigating the same. A risk register is updated regularly to reflect the strategic aims of the Board, risk mitigation by the Registry and the changing environment.

A formal disaster recovery/business continuity plan has been developed, but not fully implemented. This identifies the steps with regard to data retrieval, but not office accommodation.

Finance

Control Environment

The Board has met four times in 2013. A Senior Management Team has been formed and meets regularly. Delegated authority levels for expenditure are in place and are well understood and monitored by the Finance staff.

Information and Communication

Accounts are produced on a monthly basis and are reviewed by the Director and circulated to the relevant parties. A guide to protected disclosures has been written and circulated to all staff.

Control Activities

The Board is kept up to date with expenditure against budget through regular management accounts. Expenditure against budget is monitored on a monthly basis by the Director and Administrators. Variances against budget are discussed and actions agreed. The monthly accounts are also forwarded on to the Department of Health and Children for information and feedback.

Monitoring and Corrective Action

The monthly review of expenditure is the main way in which expenditure is monitored and corrective action decided upon.

Budgetary Control

The initial annual budget submission is made to the Department in the autumn and is based on the previous year's outturn figures in conjunction with the current year to date expenditure figures. A narrative explanation is given for any significant variances from the previous year's expenditure figures. The Department provides formal notification of the Non-Capital Expenditure allocation early in the year (typically February). The NCRB then produces a detailed monthly budget profile based on the formal allocation received from the Department along with a Service Plan for the year that details the services planned within the budget allocated. The NCRB is monitored against this plan throughout the year.

A monthly accounts pack is produced that consists of the following:

- Detailed income and expenditure account
- A balance sheet
- Budget profile for the year to date
- Variance analysis against budget

- Bank reconciliations (including bank statements)
- Summary trial balance.

Fixed Assets

a) The Fixed Asset Register is maintained on an Excel spreadsheet that is divided into the following categories:

- Software
- Hardware
- Fixtures and furnishings
- Office equipment

b) The register contains the following level of detail:

- Year of purchase
- Supplier
- Item description
- Cost
- Accumulated depreciation
- Net Book Value

The register is reconciled to the Sage accounting system on an annual basis.

Chair, National Cancer Registry Board

National Cancer Registry Ireland

STAFF

The permanent staff complement on 31/12/2013 was 37.6 FTE. In addition, 10.0 FTE were on specified contracts, 9.5 researchers funded from external sources (Health Research Board or EU) and 0.5 FTE in administration.

		WTE					number				
Job title	**Grade**	**Administration**	**Data**	**IT**	**Research**	**TRO**	**Administration**	**Data**	**IT**	**Research**	**TRO**
All staff		**5.0**	**7.5**	**4.6**	**14.4**	**16.1**	**6**	**8**	**6**	**15**	**20**
Permanent contracts											
All permanent		4.5	7.5	4.6	4.9	16.1	5	8	6	5	20
TRO Supervisor	CNM 2		0.6					1			
Clerical Officer	Grade III	1					1				
Analyst	Grade IV		1					1			
Data Quality Officer	Grade IV		2					2			
Executive Assistant	Grade IV	1					1				
Geocoding Researcher	Grade IV		1					1			
Analyst Programmer	Grade V			1					1		
Communications/HR Officer	Grade V	1					1				
Data Manager	Grade V		1.9					2			
Infrastructure Development Officer	Grade V			1					1		
Researcher	Grade V				1					1	
Statistician	Grade V				0.9					1	
IT Administrator	Grade V			0.6					1		
Administrator	Grade VI	0.5					1				
Data Analyst	Grade VI				1					1	
Analyst Researcher	Grade VII			0.5					1		
IT Specialist	Grade VII			0.5					1		
Project Leader	Grade VII		0.9					1			
IT Manager	Grade VIII			1					1		
Director	Principal Higher	1					1				
Epidemiologist	Senior Lecturer				2					2	
Tumour Registration Officer	Senior Staff Nurse					12.1					16
	Staff Nurse					4					4

Specified Purpose contracts											
		WTE					number				
Job title	**Grade**	**Administration**	**Data**	**IT**	**Research**	**TRO**	**Administration**	**Data**	**IT**	**Research**	**TRO**
Total		**0.5**			**9.5**		**1**			**10**	
Administrator	Grade VI	0.5					1				
Epidemiologist	Grade VI				1					1	
Statistician	Grade VI				1					1	
Researcher	Grade VI				1					1	
Project Co-ordinator	Grade VI				1					1	
Project Manager	Grade VI				1					1	
Research Coordinator	Grade VI				1					1	
Researcher	Grade V				0.5					1	
Statistician	Grade V				1					1	
Study Coordinator	Grade VI				1					1	
Trial Coordinator	Grade V				1					1	

ACTIVITIES

The Registry's activities fall into three main categories—data collection, reporting and research.

The database had 538,543 cases on December 31, 2013. The annual number of registrations is predicted to exceed 40,000 in 2013 (Table 1). 39,345 new cases were created in 2013 and 33,865 have been closed. The number of cases increased by 2% annually between 1994 and 2003, but has been increasing by 5% annually since then.

Table 1. Number of registrations by year (February 2014)

year	open	closed	all	predicted	% of predicted
1994	0	20,475	20,475	20733	99%
1995	1	20,544	20,545	21148	97%
1996	2	21,759	21,761	21572	101%
1997	7	22,766	22,773	22004	103%
1998	4	22,898	22,902	22445	102%
1999	6	23,445	23,451	22895	102%
2000	9	22,638	22,647	23354	97%
2001	19	23,085	23,104	23821	97%
2002	30	24,254	24,284	24299	100%
2003	27	25,314	25,341	24786	102%
2004	24	26,722	26,746	26092	103%
2005	38	26,752	26,790	27467	98%
2006	103	28,141	28,244	28914	98%
2007	85	30,557	30,642	30438	101%
2008	77	31,643	31,720	32042	99%
2009	111	33,848	33,959	33731	101%
2010	278	35,283	35,561	35508	100%
2011	3,139	34,453	37,592	37380	101%
2012	12,452	23,688	36,140	38693	93%
2013	18,364	10,490	28,854	40304	72%
2014	551	241	792	41914	2%

4.2.2. TIMELINESS

The percentage of cases first registered within a year of the date of incidence has increased from 84% in 2005 to 91% in 2012 (Table 2). Case closure lags behind this considerably; only about 40% of cases are closed within a year of the date of diagnosis. However, there are continuing small improvements in these figures since 2005.

Table 2. Interval from date of incidence to date of case creation and closure

	date of incidence to case creation			*date of incidence to date of closure*			
	<3 months	<6 months	<12 months	<3 months	<6 months	<12 months	<24 months
2005	47%	70%	84%	13%	21%	37%	63%
2006	48%	70%	85%	12%	20%	35%	70%
2007	47%	69%	86%	13%	23%	41%	70%
2008	48%	69%	86%	15%	22%	38%	73%
2009	51%	74%	88%	15%	24%	41%	75%
2010	59%	77%	88%	19%	29%	41%	74%
2011	59%	73%	87%	18%	27%	42%	75%
2012	*60%*	*73%*	*91%*	*20%*	*27%*	*43%*	*63%*
2013	*69%*	*92%*	*99%*	*23%*	*30%*	*36%*	*37%*

Figures in italics are for incomplete years

The current number of registered treatment episodes is 1,184,882 (Table 3). As with case completion, completeness of treatment registration lags behind case generation. Over 74,000 treatment episodes were added in 2012 and 42,000 in 2013.

Table 3. Treatments by type and year of treatment

year	surgery	biopsy	chemotherapy	radiotherapy	hormone	other	all
2005	17,645	11,594	4,595	3,835	2,043	8,673	48,385
2006	20,587	13,244	6,371	6,689	2,809	11,107	60,807
2007	23,039	16,066	6,970	7,160	3,028	11,517	67,780
2008	24,931	17,791	7,693	8,442	3,227	12,383	74,467
2009	27,057	19,312	8,296	8,905	3,384	13,365	80,319
2010	29,652	21,418	8,901	9,496	3,302	11,757	84,526
2011	32,445	23,454	8,584	10,146	3,597	10,127	88,353
2012	*29,200*	*20,797*	*5,857*	*8,807*	*2,378*	*7,222*	*74,261*
2013	*20,951*	*14,792*	*1,923*	*1,123*	*575*	*2,417*	*41,781*
2014	*580*	*372*	*29*	*9*	*4*	*58*	*1,052*

Figures in italics are for incomplete years

4.2.3 COMPLETENESS

For all cases combined (excluding non-melanoma skin cancer) completeness of registration was 90% at one year and 99% at five years (Figures 1 and 2). Registration of prostate cancer was considerably slower than for other common sites.

Figure 1. Estimated completeness of cases diagnosed in 2008, followed up to 2012

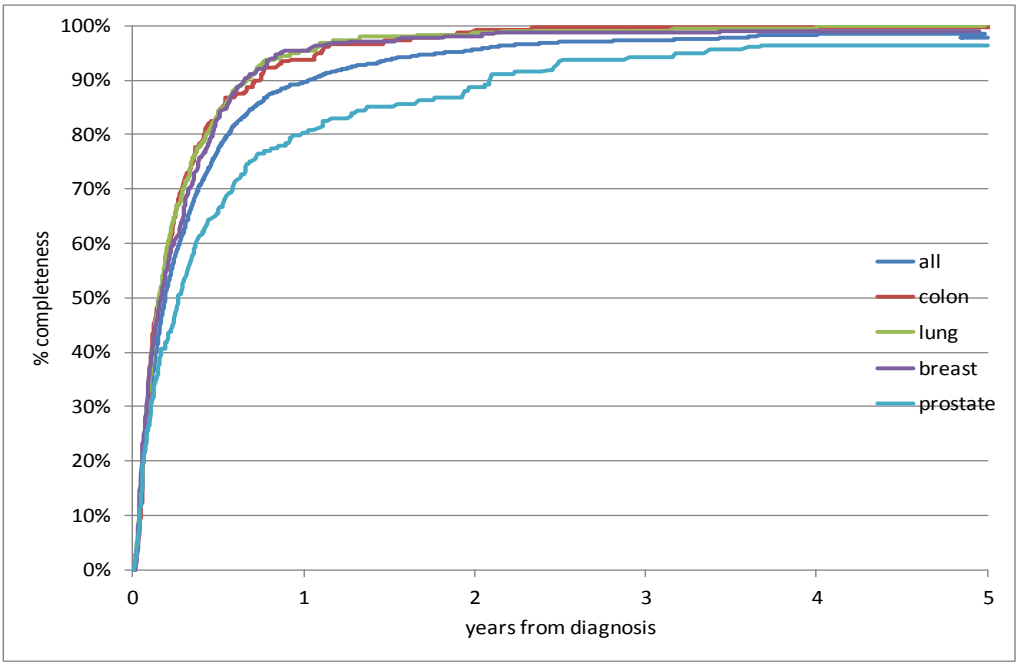
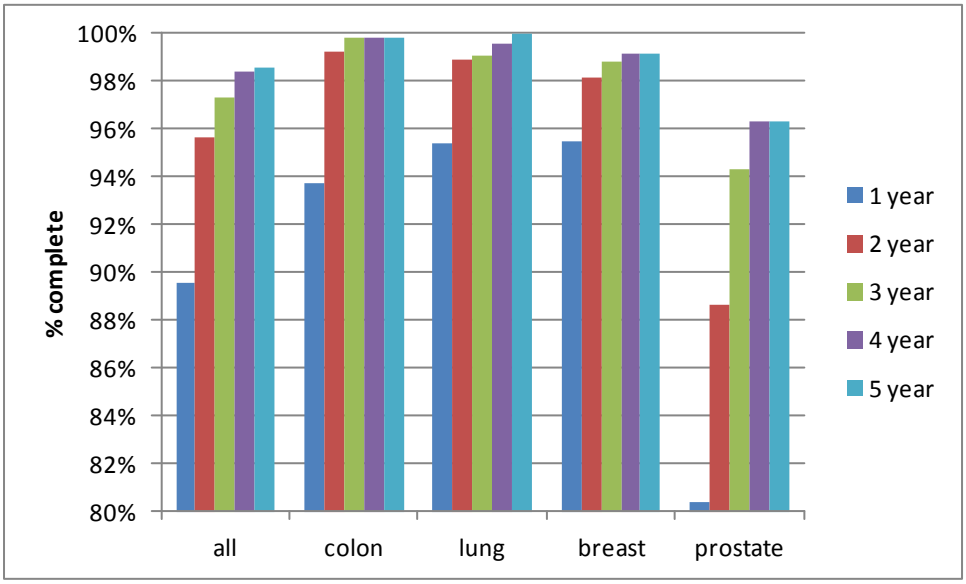


Figure 2. Estimated completeness of cases diagnosed in 2008, followed up to 2012; by years from diagnosis



Electronic data capture

Collection of data directly from electronic patient records, histopathology reports and similar sources is a more efficient and less error-prone method of registration than transcription from paper records, which remains the predominant source of data for the Registry. Few reliable sources of electronic data exist within the Irish cancer services, although the number is increasing. A joint working group has been established between the National Cancer Registry and HSE (National Cancer Control Programme, National Cancer Screening Service and ICT Directorate) to develop a plan for routine access to complete electronic histopathology data by the National Cancer Registry and CervicalCheck. A pilot project has been established in Limerick Regional Hospital and test data has been produced for validation. If successful the project will then attempt to provide data from other hospitals with the same histopathology software.

Cancer registration system

Currently the registration system has a local copy of the entire registration database on each laptop and there is a requirement on tumour registration officers to synchronise with the central database at least daily. The system was developed using technologies which are now past their end of life. The system poses major security problems as well as being very inflexible and unsuitable for the import of electronic data.

Permission was given by the Departments of Finance and Health to proceed to tender for a new Registry system based on online data entry, and this went to tender in October 2013. It is hoped that work will begin on the system in early 2014.

Disaster recovery

Currently all servers are backed up, with tapes held off-site. In the event of disaster, the plan would be to purchase new servers and rebuild the data from the tapes. This has not been tested and is not formally documented. We plan, for critical applications, to have a real-time copy at an offsite location, to have a documented Disaster Recovery plan and to test this plan yearly. At present, the IT section is determining criticality of systems and investigating options and costs for Disaster Recovery. The next steps will be to propose a Disaster Recovery solution, document response to a disaster and test the Disaster Recovery Plan.

Website

A completely redesigned website was launched in August 2013. This provides easier access to data and to registry publications.

REPORTING

The Registry provides access to data through routine reports, targeted reports, a data query service and data downloads; we provide additional information through our research programme.
All of the reports listed below can be downloaded from our website.

2013 reports

Annual statistical report

Cancer in Ireland 2013 - annual report of the National Cancer Registry.

Cancer Trends

These are brief (4-6 page) reports on a single cancer or group of cancers. Cancers reported on in 2013 were:

- Non-Hodgkin's lymphoma
- Non-melanoma skin cancer
- Hodgkin's lymphoma
- Neuro-endocrine cancers

Occasional reports

- Colorectal cancer incidence, mortality, treatment and survival in Ireland 1994-2010.

Research reports

- Report on the excess burden of cancer among men in the Republic of Ireland

RESEARCH

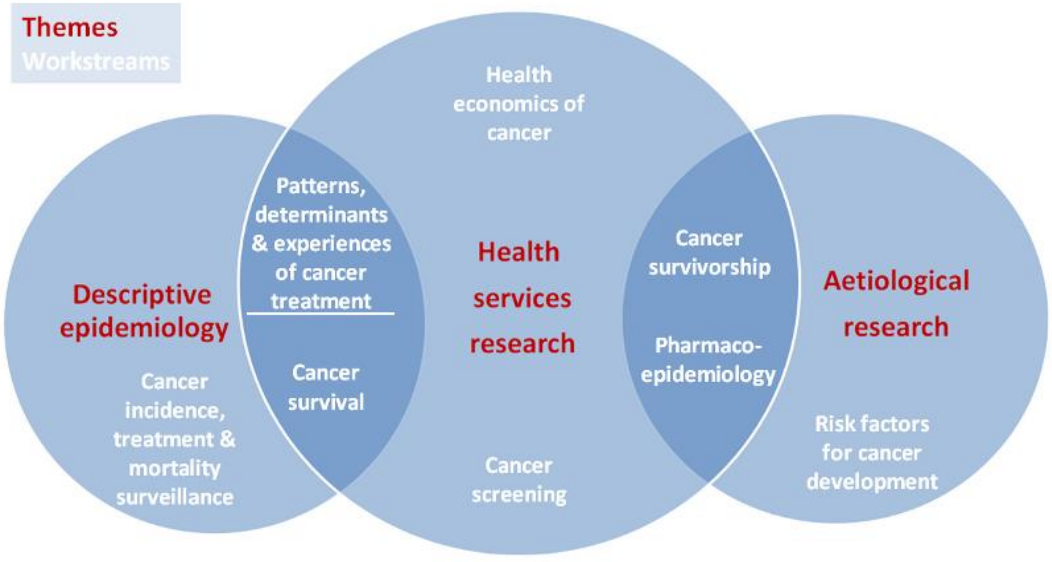
Aims

The statutory duties of the National Cancer Registry include a requirement "*to promote and facilitate the use of the data...in approved research projects and in the planning and management of services*". This obligation has been discharged though making the data widely available in anonymised format, by collaborating with researchers outside the Registry and through the Registry's internal research programme. As there is no academic research programme in cancer epidemiology at any Irish university, the use of Registry data by others has been quite limited and almost all research in the area has been carried out by the Registry either alone or in collaboration.

The primary aim of the research programme of the Registry is to provide information which will help reduce the cancer burden, through understanding of

- aetiology and risk factor prevalence;
- stage distribution of cancer and factors affecting this, including screening;
- patterns of care, their determining factors and results and patient experience;
- outcomes of cancer care, including patient-reported outcomes and long-term sequelae of cancer (survivorship), survival and economic burden (on the health services, patients and society).

Our current research strategy is focused on three central themes – descriptive epidemiology, health services research, and aetiological research.



Our research often spans more than one of these themes and so is best described in terms of the following workstreams, as outlined in the diagram above:

- Cancer incidence, treatment & mortality surveillance

- Cancer screening
- Cancer survival
- Cancer survivorship
- Health economics of cancer
- Patterns, determinants & experiences of cancer treatment
- Pharmacoepidemiology
- Risk factors for cancer development

Research and dissemination output 2013

Papers submitted during 2013 and published at 31/12/2013

1. Barron TI, Cahir C, Sharp L, Bennett K. A nested case control study of adjuvant hormonal therapy persistence and compliance, and early breast cancer recurrence in women with stage I-III breast cancer. Br J Cancer 2013; 109: 1513-21.

2. de Camargo Cancela M, Comber H, Sharp L. Hospital and surgeon caseload are associated with risk of re-operation following breast conserving surgery. Br Cancer Res Treat 2013; 140: 535-44.

3. de Camargo Cancela M, Comber H, Sharp L. Age remains the major predictor of curative treatment receipt for localised prostate cancer: a population-based study. Br J Cancer 2013; 109: 272-9.

4. Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, Rosso S, Coebergh JW, Comber H, Forman D, Bray F. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. Eur J Cancer 2013;49(6):1374-403

5. Kelly M, Sharp L, Dwane F, Kelleher T, Drummond F, Comber H. Factors predicting hospital length-of-stay after radical prostatectomy: a population-based study. BMC Health Serv Res 2013; 13(1):244

6. Lansdorp-Vogelaar I, Sharp L. Cost-effectiveness of screening and treating H. pylori for gastric cancer prevention. Best Pract Research Clinical Gastroenterol 2013; 27: 933-47.

7. Lloyd SM, Stott DJ, de Craen AJ, Kearney PM, Sattar N, Perry I, Packard CJ, Briggs A, Marchbank L, Comber H, Jukema JW, Westendorp RG, Trompet S, Buckley BM, Ford I. Long-term effects of statin treatment in elderly people: extended follow-up of the PROspective Study of Pravastatin in the Elderly at Risk (PROSPER).PLoS One 2013;8(9):e72642.

8. McDevitt J, Kelly M, Comber H, Kelleher T, Dwane F, Sharp L. A population-based study of hospital length of stay and emergency readmission following surgery for non small cell lung cancer. Eur J Cardio-Thorac Surg 2013; 44: e253-9.

9. Naidoo J, Teo MY, Deady S, Comber H, Calvert P. Should patients with extrapulmonary small-cell carcinoma receive prophylactic cranial irradiation? J Thorac Oncol 2013;8(9):1215-21

10. O'Brien K, Sharp L. Trends in incidence of, and mortality from, cervical lesions in Ireland: baseline data for future evaluation of the national cervical screening programme. Cancer Epidemiol 2013; 37: 830-5.

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12. Sharp L, Cotton S, Little J, Gray NM, Cruickshank M, Smart L, Thornton A, Waugh N, Walker L, on behalf of the TOMBOLA group. Psychosocial impact of alternative management policies for low-grade cervical abnormalities: results from the TOMBOLA randomised controlled trial. PLoS ONE. 8(12):e80092.

13. Spillane S, Bennett K, Sharp L, Barron TI. A cohort study of metformin exposure and survival in patients with stage I-III colorectal cancer. Cancer Epidemiol Biomarkers Prev 2013; 22: 1364-73.

14. Timmons A, Gooberman-Hill R, Sharp L. "It's at a time in your life when you are most vulnerable": a qualitative exploration of the financial impact of a cancer diagnosis and implications for financial protection in health. PLoS One 2013; 8: e77549

15. White C, Keegan H, Pilkington L, Ruttle C, Kerr P, Sharp L, O' Toole S, Turner M, Prendiville W, D'Arcy T, Fitzpatrick M, Lenehan P, Flannelly G, O' Leary JJ, Martin CM. Evaluation of the clinical performance of the cobas® 4800 HPV test in a colposcopy referred population. J Clin Microbiol 2013; 51: 3415-7.

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16. Arnold M, Holterhues C, Hollestein LM, Coebergh JW, Nijsten T, Pukkala E, Holleczek B, Tryggvadóttir L, Comber H, Bento MJ, Diba CS, Micallef R, Primic-Žakelj M, Izarzugaza MI, Perucha J, Marcos-Gragera R, Galceran J, Ardanaz E, Schaffar R, Pring A, de Vries E. Trends in incidence and predictions of cutaneous melanoma across Europe up to 2015. J Eur Acad Dermatol Venereol (in press)

17. Bannon FJ, McCaughan JA,, Traynor C, O'Brien K, Gavin AT, Maxwell AP, Comber H, Conlon PJ. Surveillance of non-melanoma skin cancer incidence rates in kidney transplant recipients in Ireland. Transplantation (in press)

18. Donnelly D, Hegarty A, Sharp L, Carsin A-E, Deady S, McCluskey N, Comber H, Gavin A. The impact of adjustment for socio-economic status on comparisons of cancer incidence between two European countries. J Cancer Epidemiol (in press)

19. Drummond FD, Barrett E, Burns R, O'Neill C, Sharp L. The number of tPSA tests continues to rise and variation in testing practices persists: A survey of laboratory services in Ireland 2008-2010. Ir J Med Sci (in press)

20. Drummond FD, O'Leary E, O'Neill C, Burns R, Sharp L. 'Bird in the hand.' Cash was more effective than prize draws in increasing physician questionnaire response rate. J Clin Epidemiol (in press)

21. Flahavan EM, Bennett K, Sharp L, Barron TI. A cohort study investigating aspirin use and survival in men with prostate cancer. Ann Oncol (in press).

22. Flahavan EM, Sharp L, Bennett K, Barron I. A prospective cohort study of digoxin use and prostate cancer mortality. Br J Urol International (in press)

23. Gurumurthy M, Cotton SC, Sharp L, Little J, Cruickshank ME, on behalf of the TOMBOLA group. Post-colposcopy management of women with biopsy-proven CIN1: Results from TOMBOLA. J Lower Gen Tract Disease (in press)

24. Jennings CJ, Walsh PM, Deady S, Harvey BJ, Thomas W. Malignant pleural mesothelioma incidence and survival in the Republic of Ireland 1994-2009. Cancer Epidemiol (in press)

25. Lortet-Tieulent, Renteria E, Sharp L, Weiderpass E, Comber H, Baas P, Bray F, Soerjomataran I. Convergence of male and female incidence rates in major tobacco-related cancers in Europe in 1988-2010. Eur J Cancer (in press)

26. O'Brien K, Comber H, Sharp L. Data completeness at the Irish National Cancer Registry. Irish Med J (in press)

27. O'Connor M, Costello L, Murphy J, Prendiville W, Martin CM, O'Leary JJ, Sharp L. "I don't care whether it's HPV or ABC, I just want to know if I have cancer." Factors influencing women's emotional responses to undergoing HPV testing in routine management in cervical screening. Br J Obstet Gynecol (in press)

28. Sharp L*, Cotton S*, Cruickshank M, Gray NM, Harrild K, Smart L, Walker L, Little J, on behalf of the TOMBOLA group. The unintended consequences of cervical screening: distress in women undergoing cytological surveillance. (*joint principal authors). J Lower Genital Tract Disease (in press)

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1. Barron TI, Flahavan EM, Sharp L, Bennett K, Visvanathan K. Aspirin use, lymph node metastasis and mortality in women with stage I-III breast cancer: a prospective cohort study. Cancer Res

2. Burns RM, Sharp L, Sullivan FJ, Deady SE, Drummond FJ, O'Neill CE. Factors driving inequality in prostate cancer survival: A population based study. J Cancer Surv

3. Clarke N, McDevitt J, Kearney P, Sharp L. Increasing late stage and mortality of colorectal cancer demonstrates the need for screening: a population based study in Ireland, 1994-2010. BMC Gastroenterol

4. Cotton SC*, Sharp L*, Little J, Gray NM, Walker LG, Whynes DK, Cruickshank ME, on behalf of the TOMBOLA Group. How reassuring is a normal colposcopy examination for women who have had low-grade abnormal cervical cytology? Results from TOMBOLA. Cytopathol (*joint principal authors)

5. Cruickshank ME, Cotton SC, Sharp L, Smart L, Walker LG, Little J, on behalf of the TOMBOLA Group. Management of women low grade cytology: How reassuring is a normal colposcopy examination? Br J Obstet Gynaecol

6. Deady S, Sharp L, Comber H. Increasing skin cancer incidence in young, affluent, urban populations: a challenge for prevention. Br J Dermatol

7. Dee A, Kearns K, O'Neill C, Sharp L, Staines A, Perry I. Review of the direct and indirect costs of overweight and obesity. BMC Public Health

8. Flahavan EM*, Drummond FD*, Bennett K, Barron I, Sharp L, An investigation of associations between prostate specific antigen testing and men's socio-demographic characteristics, healthcare utilization and physical, mental and emotional health. (* joint first authors). Eur J Gen Pract

9. Hanly P, O'Ceilleachair A, Skally M, O'Neill C, Sharp L. Costs of radiotherapy for rectal cancer: is there potential for efficiency savings? A microcosting study. J Health Service Research Pract

10. Hanly P, Sharp L. The cost of lost productivity due to premature cancer-related mortality: an economic measure of the cancer burden. BMC Cancer

11. McRae J, Martin C, O'Leary J, Sharp L. "If you can't treat HPV, why test for it?" Women's attitudes to the changing face of cervical cancer prevention: a focus group study. BMC Women's Health

12. McSherry LA, Dombrowski SU, Francis J, Murphy J, Martin CM, O'Leary JJ, Sharp L for the ATHENS Group. Maximising cervical screening: what influences the behaviours of GPs and practice nurses? Eur J Gen Pract

13. O'Connor M, Costello L, Murphy J, Prendiville W, Martin CM, O'Leary JJ, Sharp L. Information barriers and factors influencing information needs among women having HPV tests as part of routine follow-up for abnormal cervical cytology. J Fam Planning Reprod Health Care

14. O'Connor M, Murphy J, Martin C, O'Leary J, Sharp L, on behalf of the Irish Cervical Screening Consortium (CERVIVA). Motivators for women to attend cervical screening: the influential role of general practitioners. Fam Pract

15. O'Toole A, Walsh PM, Keegan D, Byrne K, Doherty G, O'Donoghue D, Mulcahy H. Mortality in inflammatory bowel disease patients under 65 years of age. Inf Bowel Dis

16. Rothnie K, Cotton SC, Fielding S, Gray NM, Little J, Cruickshank ME, Walker L, Avis M, Sharp L, in association with the TOMBOLA group. Measuring the psychosocial burden in women with low-grade abnormal cervical cytology in the TOMBOLA trial: psychometric properties of the Process and Outcome Specific Measure (POSM). Qual Life Res

17. Shafer LS, Nsubuga RN, Chapman R, O'Brien K, Mayanja BN, White RG. Antiretroviral therapy, sexual behavior, and their simulated impact on HIV epidemiologic trends in Uganda. Lancet Infectious Diseases. Sex Trans Infect

18. Sheridan J, Doherty G, Walsh PM, Kevans D, Keegan D, Nolan B, White A, McDermott E, Sheahan K, O'Shea D, Hyland J, O'Donoghue D, O'Sullivan J, Mulcahy H. Determinants of short and long term survival from colorectal cancer in very elderly patients. J Ger Oncol

19. Thomas AA, Timmons A, Molcho M, Gallagher P, Pearce A, Butow P, O'Sullivan E, Gooberman-Hill R, O'Neill C, Sharp L. Quality of life in urban and rural settings: A study of head and neck cancer survivors. Oral Oncol

20. White C, Bakhiet S, Bates M, Keegan H, Pilkington L, Ruttle C, Sharp L, O'Toole S, Fitzpatrick M, Lenehan P, Flannelly G, O'Leary J, Martin M. Utility of p16/Ki-67 dual staining and HPV testing in the triage of minor abnormal cytology: a two year prospective study. Lancet Oncol

21. Comber H, O'Connor A. Cancer risk perception and potential cancer hazard in two Irish communities. Cancer Epidemiology.

22. Steliarova-Foucher E, O'Callaghan M, Ferlay J, Masuyer E, Forman D, Bray F, Comber H. The European Cancer Observatory: a new data resource. Eur J Cancer

23. Siesling 2, Louwman M, Kwast A, van der Hurk C, Rosso S, Zanetti R Storm H, Comber H, Steliarova-Foucher E,Coebergh JWW. Analysis of coverage, data availability and research of cancer registries in Europe. Eur J Cancer

2013 Conference Presentations

Invited conference presentations made by NCR staff

1. Drummond FJ. PSA testing in Ireland, 2008-2010 A laboratory survey. IEQAS, Annual Participants' Conference Dublin, October 3rd 2013,

2. Drummond FJ. Results from the PiCTure study. Irish Association of Urology Nurses, Dublin, 11-12th October 2013.

3. Sharp L. Setting the scene: epidemiology of head and neck cancer in Ireland. HPV and Head and Neck Cancer Symposium: Clinical & Public Health Considerations. NUI Galway, Galway University Hospitals and Health Research Board, Galway, 17th May 2013.

4. Sharp L. Cancer data and resources for research. Economics of Cancer Research Symposium. NUI Galway, Galway University Hospitals and Health Research Board, Galway, 2nd September 2013.

5. Sharp L. Returning to work after cancer: what influences it and why is it important? ECCO Patient Track. European Multidisciplinary Cancer Congress, Amsterdam, 27th September-1st October 2013.

6. Sharp L. Men's experiences of prostate cancer care in Ireland: results from the PiCTure 2 study. National Cancer Control Programme Annual Prostate Cancer Forum, Dublin, 8th November 2013.

Oral presentations or poster presentations made by NCR staff

7. Drummond FJ, Kinnear K, O'Leary E, O'Brien K, Gavin A, Sharp L. Actual and expected treatment-related side-effects predict low health related quality-of-life in prostate cancer survivors PiCTure study. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June 2013.

8. Drummond FJ, Kinnear K, O'Leary E, O'Brien K, Gavin A, Sharp L. Health related quality of life in prostate cancer survivors decreased with time since diagnosis. NCIN Cancer Outcomes Conference, Brighton, 12-14th June, 2013.

9. Drummond FJ, Kinnear H, O'Leary E, Gavin A, Sharp L. Does the long-term effect of a prostate cancer diagnosis differ in men who were screen-detected or symptomatic at diagnosis: Results from an all-Ireland survey".10th Annual Psychology, Health and Medicine Conference, Dublin, Ireland, 1st May 2013.

10. Drummond FJ, Kinnear H, O'Leary E, Gavin A, Sharp L. Associations between method of detection, clinical and socio-demographic factors and psychological well-being among prostate cancer survivors. Irish Society of Urology Annual Meeting, Wicklow, 20th-21st September 2013

11. Drummond FJ, Kinnear H, Sharp L, Gavin A. An all-Ireland population-based study of past and current physical and psychological side-effects following prostate cancer treatments. Irish Society of Urology Annual Meeting, Wicklow, 20th-21st September 2013

12. Hanly P, Sharp L. The cost of lost productivity due to premature cancer-related mortality: an alternative measure of the cancer burden. NCIN Cancer Outcomes Conference, Brighton, 12-14th June, 2013

13. Hennessy M, Comber H, Drummond FJ, Sharp L. Insights into the care experiences of men with prostate cancer in Ireland. RCSI Faculty of Nursing and Midwifery 32nd International Nursing Research Conference, Dublin, 20th-21st February 2013.

14. Hennessy M, O' Leary E, Comber H, Drummond FJ, Sharp L. Adapting the Prostate Care Questionnaire to measure men's experiences of prostate cancer care in Ireland. PROMs Summit, London, 14th November 2013.

15. McSherry L, Dombrowski S, O'Leary E, Francis J, Murphy J, Martin C, O'Leary J, Sharp L for the ATHENS Group. HPV-related attitudes & behaviours of GPs and practice nurses. Preliminary survey results. British Society for Cervical Cytology and Pathology, Glasgow, 24th-26th April 2013.

16. McSherry L, Dombrowski S, Francis J, Martin C, O'Leary J, Sharp L. The impact of HPV-related attitudes on behaviours of GPs and practice nurses: results from ATHENS (A Trial of HPV EducatioN and Support). UK Society of Behavioural Medicine, Oxford, 9-10th December 2013.

17. O'Connor M, O'Leary E, Murphy J, White C, Ruttle C, Martin C, Flannelly G, von Bunau G, O'Leary J, Pilkington L, Anglim L, Turner M, Farah N, Cleary S, Darcy T, Prendiville W, Sharp L, on behalf of the Irish Cervical Screening Research Consortium. Prevalence and predictors of anxiety and worries in women following colposcopy: results from a longitudinal study. British Society for Cervical Cytology and Pathology, Glasgow, 24th-26th April 2013.

18. O'Connor M, Costello L, Murphy JC, Hayes Jordan D, Murphy J, Bastick P, Farrar K, Martin M, Prendiville W, Sharp L, on behalf of the Irish Cervical Screening Research Consortium (CERVIVA). "I don't care what it's called, I don't care whether it's HPV or ABC, I just want to know if I have cancer." Women's emotional responses and information needs after having a HPV test. Psychology, Health & Medicine 10th annual conference, Dublin, 1st May, 2013.

19. O'Connor M, White C, Ruttle C, Martin C, Flannelly G, von Bunau G, O'Leary J, Pilkington L, Turner M, Farah N, Cleary S, Darcy T, Prendiville W, Murphy J, Sharp L. Prevalence and predictors of anxiety and worry in women after colposcopy: a longitudinal study. UK Society Behavioural Medicine, Oxford, 9-10th December 2013.

20. Sharp L, O'Driscoll D, O'Leary E, Higney K, Bradley C. Patterns and predictors of workforce participation in cancer survivors 6 and 12-months post-diagnosis: a longitudinal study. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June 2013.

Poster presentations made by NCR staff

21. Comber H, O'Connor A. Cancer risk perception and potential cancer hazard in two Irish communities. 35th International Association of Cancer Registries Conference, Buenos Aires, 22nd-24th October 2013.

22. Drummond FJ, Kinnear H, O'Leary E, Gavin A, Sharp L. Strong but not so silent. Experiences of providing a freephone number with a postal survey of prostate cancer survivors. 10th Annual Psychology, Health and Medicine Conference, Dublin, 1st May 2013.

23. Drummond FJ, Kinnear H, Craven-Lynn A, Gavin A, Sharp L. Men talk! Our experience of using a freephone number with a postal questionnaire. NCIN Cancer Outcomes Conference, Brighton, 12-14th June, 2013.

24. Drummond FJ, Kinnear H, O'Leary E, Gavin A, Sharp L. An all-Ireland population-based study of immediate and current physical and psychological side-effects of prostate cancer treatments. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June, 2013.

25. Drummond FJ, Kinnear H, O'Brien K, Gavin A, Sharp L. Time since diagnosis and health related quality of life in prostate cancer survivors in Ireland. National Cancer Research Institute, Liverpool, 3rd-6th November 2013.

26. Drummond FJ, Kinnear H, Craven-Lynn A, Gavin A, Sharp L. Strong but not so silent. Experiences of providing a freephone number with a postal survey of prostate cancer survivors. National Cancer Research Institute, Liverpool, 3rd-6th November 2013.

27. Drummond FJ, Kinnear H, O'Brien K, Gavin A, Sharp L. Association between clinical and socio-demographic factors and methods of detection with psychological well-being among prostate cancer survivors. International Psycho-oncology Society, Amsterdam 3rd-8th November 2013.

28. Hennessy M, O' Leary E, Comber H, Drummond FJ, Sharp L. Factors that influence men's experiences of prostate cancer care: Preliminary results of a national study. Cancer Outcomes Conference, Brighton, 12-14th June 2013.

29. Hennessy M, O' Leary E, Comber H, Drummond FJ, Sharp L. Associations between men's experiences of prostate cancer care and health related quality-of-life and psychological wellbeing: findings from a national study. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June 2013.

30. Hennessy M, Comber H, Drummond FJ, Sharp L. Men's experiences of prostate cancer care: qualitative findings from cognitive interviews. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June 2013.

31. Hennessy M, Comber H, Drummond FJ, Sharp L. Men's experiences of prostate cancer care in Ireland: Insights from the pre-testing of a national survey. Irish Cancer Society Survivorship Research Day, Dublin, 19th September 2013.

32. Hennessy M, O' Leary E, Comber H, Drummond FJ, Sharp L. Prostate cancer patients' perspectives on quality-of-care: their care experiences, health-related quality-of-life and psychological well-being. 35th International Association of Cancer Registries Conference, Buenos Aires, 22nd-24th October 2013.

33. Hennessy M, O' Leary E, Comber H, Drummond FJ, Sharp L. Associations between overall care experience ratings and utility and psychological well-being in men recently diagnosed with prostate cancer: findings from a population-based study. International Society for Pharmacoeconomics and Outcomes Research 16th Annual European Congress, Dublin, 2nd-6th November 2013.

34. McSherry L, O'Leary E, Dombrowski S, Francis J, Martin C, O'Leary J, Sharp L. Predictors of HPV knowledge among GPs and practice nurses: results from ATHENS (A Trial of HPV EducatioN and Support). British Society for Cervical Cytology and Pathology, Glasgow, 24th-26th April 2013.

35. O'Connor M, O'Leary E, Murphy J, Martin CM, O'Leary JJ, Sharp L, on behalf of the Irish Cervical Screening Research Consortium (CERVIVA). Women's expected adverse emotional reactions to testing HPV positive: results from a national population survey in Ireland. British Society for Cervical Cytology and Pathology, Glasgow, 24th-26th April 2013.

36. O'Connor M, O'Leary E, Murphy J, White C, Ruttle C, Martin C, Flannelly G, von Bunau G, O'Leary J, Pilkington L, Anglim L, Turner M, Farah N, Cleary S, Darcy T, Prendiville W, Sharp L, on behalf of the Irish Cervical Screening Research Consortium (CERVIVA) .Psychological after-effects of colposcopy: preliminary results from a longitudinal study. Psychology, Health & Medicine 10th annual conference, Dublin, 1st May, 2013.

37. O'Connor M, O'Leary E, Murphy J, White C, Ruttle C, Martin C, Flannelly G, von Bunau G, O'Leary J, Pilkington L, Anglim L, Turner M, Farah N, Cleary S, Darcy T, Prendiville W, Sharp L, on behalf of the Irish Cervical Screening Research Consortium (CERVIVA). Associations between psychological and physical after-effects in women undergoing colposcopy and related procedures for follow-up for an abnormal cervical smear. International Psycho-Oncology Conference 2013, Rotterdam, 4-8th November, 2013.

38. O'Connor M, O'Leary E, Murphy J, White C, Ruttle C, Martin C, Flannelly G, von Bunau G, O'Leary J, Pilkington L, Anglim L, Turner M, Farah N, Cleary S, Darcy T, Prendiville W, Sharp L, on behalf of the Irish Cervical Screening Research Consortium (CERVIVA). Prevalence and predictors of anxiety and worry in women after colposcopy: a longitudinal study. International Psycho-Oncology Conference 2013, Rotterdam, 4-8th November, 2013.

39. Pearce A, Timmons A, Hanly P, O'Neill C, Sharp L, in association with ICE Cancer Survivorship Award Investigators and SUN Study Investigators. Workforce participation and productivity losses after head and neck cancer. International Society for Pharmacoeconomics and Outcomes Research 16th Annual European Congress, Dublin, 2nd-6th November 2013.

40. Sharp L, O'Driscoll D, O'Leary E, Higney K, Bradley C. Patterns and predictors of workforce participation in cancer survivors 6-months and 12-months post-diagnosis: results from the longitudinal CaRE (Cancer and Return to Employment) study. Irish Cancer Society Survivorship Research Day, Dublin, 19th September 2013.

41. Sharp L, Shearer N, Leen R, O'Morain C, McNamara D. Prevalence and predictors of colonoscopy-related distress in individuals undergoing FIT-based colorectal cancer screening: a population-based study. Irish Society of Gastroenterology, Winter Meeting, 22nd-23rd November 2013.

42. Timmons A, Gooberman-Hill R, O'Sullivan E, Butow P, Sharp L. Why are supportive care needs of survivors of head & neck cancer not being met? Barriers perceived by health professionals. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June 2013.

43. Timmons A, Gooberman-Hill R, O'Sullivan E, Butow P, Sharp L. "Silent heroes": the importance of informal caregivers in supportive care of survivors of head & neck cancer. MASCC/ISOO International Symposium on Supportive Care in Cancer, Berlin, 27-29th June 2013.

44. Timmons A, Sharp L. Identifying cancer survivors at increased risk of financial stress and strain as a result of having cancer. Irish Cancer Society Survivorship Research Day, Dublin, 19th September 2013.

Grant/funding applications submitted in 2013

Successful applications made in 2013

1. Gallagher P, Sharp L, Desmond D, Coffey L, Timon C. Self-management for head and neck cancer survivors: Living well with and beyond head & neck cancer. Irish Cancer Society Survivorship Research Projects. €300,000. 2014-2016.

2. Gavin A, Kinnear H, Drummond FJ, Gormley G, Sharp L. Understanding how to improve the lives of men living with prostate cancer: Analysis of data on 3,504 Prostate Cancer Survivors to investigate men's experiences and physical and emotional wellbeing. Prostate Cancer UK. £109,000. 2014-2015

3. Galvin D, McDermott R, Sharp L, Sullivan F. Irish Prostate Cancer Outcomes Research (IPCOR). Irish Cancer Society. €1.75 million. 2014-2019

Unsuccessful applications made in 2013

4. Miedzybrodska Z , Little J, Sharp L, Dunlop M. Unravelling the genetic aetiology of colorectal polyps. Association for International Cancer Research. £180,000 over 18 months

5. Sharp L, Capra M, Gooberman-Hill R, Hennessy M, Kiernan G. Are the supportive care needs of survivors of childhood cancer and their families being met? Informing the development of effective supportive care services for childhood cancer. National Children's Research Centre. €300,000 over 3 years.

6. de Camargo Cancela M, Sharp L. Translating basic science into improved outcomes for prostate cancer patients: investigating the effects of antiplatelets, anticoagulants and beta-blockers on tumour growth, metastases and mortality. Irish Cancer Society Post-Doctoral fellowship. €228,201 over 3 years.

Applications made in 2013 for which decision pending

7. Hayes C, Bennett K, Sharp L, Kenny RA. Health behaviours and quality of life in older cancer survivors in The Irish Longitudinal Study on Ageing (TILDA). Health Research Board. €330,000 over 3 years.

Full and short reports published in 2013

Full reports published 2013

- Clarke N, Sharp L, O'Leary E, Richardson N. A report on the excess burden of cancer among men in the Republic of Ireland. National Cancer Registry/Carlow Institute of Technology/Irish Cancer Society, Dublin, 2013

- Colorectal cancer incidence, mortality, treatment and survival in Ireland 1994-2010. National Cancer Registry, Cork, 2013 (McDevitt J, Walsh P, Comber H)

- Cancer in Ireland 2013 - annual report of the National Cancer Registry. National Cancer Registry, Cork, 2013 (Deady S, McDevitt J, Comber H)

National Cancer Registry Ireland

Cancer trends short reports published 2013

1. Non-Hodgkin's lymphoma (Deady S, Comber H)
2. Non-melanoma skin cancer (Deady S, Comber H)
3. Hodgkin's lymphoma (Deady S, Comber H)
4. Neuroendocrine tumours (Deady S, Comber H)

STRATEGIC PLANNING 2013-2016

Background

With the appointment of a new National Cancer Registry Board, and the anticipated retirement of the current Director in 2014, the Board has decided to refresh and broaden its current strategic plan, to take into account the changing health services and research environment in Ireland. As part of this process the Board has carried out a wide consultation, including a survey of the views of a range of key bodies and individuals on the current and future role of the Registry.

Some key elements to emerge from this consultation were:

- Clinicians should have a greater role in advising the Registry, for instance though the establishment of an Advisory Committee.
- The Registry should have more engagement with clinicians and the public.
- The Registry should retain its autonomy as far as possible.
- Data collection and availability should be more timely.
- Registration of cancer should be mandatory.
- The routine dataset should be expanded to include, for instance, family history and risk factors.
- The Registry should attempt to provide follow-up information on patients.
- Data should be made as widely available as possible.
- Research using both registration data and additional data should be encouraged.

The following 3 year statement of strategy was agreed by the Board in December 2013.

Statement of strategy 2013-2016

Aims

1. To collect accurate, timely and comprehensive data through cancer registration and related research activities.
2. To disseminate data and the results of analysis in a relevant and comprehensive manner.

Challenges

The Board identified a number of key strategic challenges for the Registry.

1. To identify the optimum setting for the Registry at a time of reorganisation and reform of public and health services.
2. To maintain and improve the quality of data and research output from the Registry at a time of change and financial restrictions within the health services.
3. To make the Registry more relevant to service planning and clinical practice to the ultimate benefit of cancer patients.

Strategic Objectives

The Board has agreed a number of strategic objectives related to these challenges

1. **Optimum setting for the Registry**
    a. Any arrangements should be sustainable and must allow the Registry to remain independent in its reporting of data.
    b. In consultation with the Minister for Health, his officials, management of the HSE and others, to agree a long-term configuration and governance arrangement for the Registry. These might include continuing as an autonomous agency of the Department of Health, integration with the Department of Health, integration with a health intelligence or public health agency, merging with the National Cancer Control Progamme or an academic partnership.
    c. To explore the possibilities of closer links with academic bodies within Ireland with a view to developing closer collaborations in research, data analysis and methodology, as well as enhancing the career possibilities of Registry researchers.
2. **Maintain and improve the quality of data and research output from the Registry**
    a. Build partnerships and capacity in health intelligence and cancer services research.
    b. Increase the level of engagement with registries and other bodies in the rest of Europe and beyond.
    c. Encourage wide participation and collaboration in research.
    d. Keep the Registry at the forefront of registration and research development internationally.
    e. Explore the potential of closer academic integration, while avoiding identification with any single academic institution.
3. **Make the Registry more relevant to service planning and clinical practice**
    a. Establish processes of regular and effective engagement with clinicians and hospital groups to determine how the Registry might assist them, and they the Registry.
    b. Provide regular outputs.
    c. Explore methods of collecting data in a more timely way.
    d. Examine the feasibility of extending the Registry dataset, particularly with regard to follow-up data.
    e. Increase the visibility of the Registry and registration data to the public, to clinicians and in supporting planning, monitoring and evaluation of services.
    f. Work toward greater availability and sharing of data across the cancer services and reduction of duplication in data collection and reporting.
    g. Enhance public awareness of the Registry and its work.

Strategic Actions

1. **Optimum setting for the Registry**
    a. Initiate discussions with key individuals on the future of the Registry
    b. Appoint a new Registry Director with the skills and experience to lead and develop the Registry through this transitional phase and maximise the opportunities arising from any reconfiguration.
    c. To initiate discussions with academic bodies within Ireland on the potential for collaboration at various levels, including shared posts, shared facilities and collaborative research programmes.

2. **Maintain and improve the quality of data and research output from the Registry**
    a. Establish a cancer information committee in each hospital group to explore more efficient access to data and use of resources locally.
    b. Advocate for the Health Information Bill and for cancer registration to be made mandatory.
    c. Work with
        - hospital and HSE IT to increase the availability and quality of electronic data from histopathology, oncology, radiotherapy and similar systems;
        - ESRI to improve access to HIPE data;
        - Private health insurers to provide claims data.
    d. Enhance the Registry website to improve access to data.
    e. Increase the output of peer-reviewed papers.
    f. Encourage attendance of Registry staff to present research and analysis at clinical conferences.
    g. Work with academic and research institution to develop collaborative research both in Ireland and abroad.
3. **Make the Registry more relevant to service planning and clinical practice**
    a. Establish a Clinical Advisory Group, in collaboration with the National Cancer Control Programme, to explore areas of mutual interest with the cancer clinical community, including more collaboration in data collection, additional data items and more focussed reporting.
    b. Consult with the Department of Health, National Cancer Control Progamme, HSE and other relevant bodies on the type and content of outputs they would like to have from the Registry.
    c. Develop the Registry's capacity in health economics and service assessment.
    d. Develop capacity in data management linkage and analysis, in areas of relevance to planning, monitoring and evaluation of cancer services.

PERFORMANCE INDICATORS

A set of performance indicators was agreed by the Board in 2010 to evaluate the success of the registry in attaining the objectives set out in the strategic plan. The targets were chosen to be slightly better than current performance in most areas. Performance on these indicators is shown below for the most recent year available. Indicators which did not reach the agreed target are shown in red.

Aims

1. To provide a suite of indicators to measure the performance of the National Cancer Registry in delivering on the strategic plan.
2. To benchmark the performance of the National Cancer Registry against similar bodies.

Registration

Timeliness

50% of invasive cancers, excluding non-melanoma skin, should be registered within 3 months of the date of incidence.	2010 2009	58.9% 50.1%
90% of invasive cancers, excluding non-melanoma skin, should be registered within 12 months of the date of incidence.	2010 2009	88.1% 87.9%
90% of invasive cancers, excluding non-melanoma skin, should be closed within 24 months of the date of incidence.	2010 2009	77.6% 77.4%

Accuracy

Death certificate only cases should be <1% of the total of all invasive cancers, excluding non-melanoma skin	2011	0.17%
90% of all invasive cancers, excluding non-melanoma skin, should be microscopically verified, if the case is closed.	2011	91.1
Cancers of ill-defined sites should be less than 3% of all invasive cancers, excluding non-melanoma skin.	2011	2.7%

Completeness

Registration completeness, as assessed by the flow method, for all invasive cancers excluding non-melanoma skin cancer, should be • 90% at one year, • 96% at two years • 98% at five years from the end of the year of registration	2008 90% 96% 99%

Research and Dissemination

1. Provide data for CI5, EUROCIM, EUROCARE and similar projects on time and as requested

- Dataset on ten major cancer types (1994-2009 cases with follow-up to end of 2010) was submitted to the CONCORD-2 international survival study on 12 April 2013.
- Dataset on treatment and survival of breast cancer patients (2003-2009 cases with follow-up to end of 2010) was submitted to EURECCA-breast-pilot project (EUropean REgistration of Cancer Care) on 4 April 2013.

2. Publish peer-reviewed papers in high impact journals

(a) Submit at least 12 papers (on which an NCR staff member is first/last/senior author) for publication in peer-reviewed journals.

- Number of papers published/in press 2013 on which NCR staff member was first or last/senior author: 15 (out of 30 papers)
- Number of papers submitted in 2013 and under review at 31/12/2013 on which NCR staff member was first or last/senior author: 13 (out of 20 papers)

(b) Make at least 24 oral and poster presentations at national and international conferences.

- Number of conference presentations (invited, oral or poster) by NCR staff in 2013: 44

3. Lead, or collaborate in, the submission of at least 4 grant/funding applications.

- Number of grant/funding applications made in 2013: 7

4. Complete 80% of queries within 2 weeks of receipt.

- 252 queries dealt with in 2013; 261 (86%) replied to within 1 week; 23 (9%) replied to between 1 and 2 weeks; 13 (5%) replied to after 2 weeks (2 requests took 5 & 6 weeks)

5. Produce reports based on registry data, including: (a) four short reports on cancer trends; and (b) the registry annual report.

- Number of full reports published in 2013: 3 (including annual report)
- Number of short reports published in 2013: 4

Administration

1. The annual accounts and report of the Board to be produced by June 30th

No. Audited accounts were not available until October 2013.

2. Service plan to be delivered to the Department of Health within 4 weeks of letter of allocation

Yes

3. Registry expenditure to remain within assigned annual budget

Yes

4. Deliver on all recommendations in internal audit reports within timeframe agreed

No. The Audit Committee considered that not all recommendations were practicable, given the limited resources of the Registry .

OVERVIEW OF ENERGY USAGE IN 2013

The main energy users at the National Cancer Registry are air conditioning and heating. Other uses include lighting, office equipment and catering. All of these are powered by electricity and there is no consumption of gas or fossil fuels for any purpose. It is not possible to apportion electricity consumption between these various uses, as they come off the same supply.

In 2013, the National Cancer Registry consumed 88.326 MWh of energy, all electrical.

Actions Undertaken in 2013

In 2013 the Registry undertook a range of initiatives to improve our energy performance, including:

- Decreased use of heating and air-conditioning by judicious use of natural heating and cooling;
- Powering down of all non-essential IT equipment when not in use.

National Cancer Registry Ireland

ANNUAL ACCOUNTS 2013

Income from the Department of Health in 2013 was €2.444K, down from €2.475k in 2012. Other income consisted of retained superannuation income and income from research grants. Expenditure in 2013 was €3.122K, down from €3.196 in 2012. There was an overall surplus of income over expenditure for 2013 of €39K.

National Cancer Registry Board

Draft Income and Expenditure Account

for the year ended 31st December 2013

	2013 **€**	2012 €
Income		
Department of Health	**2,444,000**	2,475,000
Superannuation contributions	**103,156**	99,110
Other Income	**614,277**	639,732
Total Income	**3,161,433**	3,213,842
Expenditure		
Staff costs	**2,596,863**	2,621,628
Administration costs	**481,959**	527,453
Travel and subsistence	**49,202**	47,214
Total Expenditure	**3,128,024**	3,196,295
Surplus/(Deficit) for year	**33,409**	17,547
Balance Brought forward 1st January	**88,663**	71,116
Balance Carried Forward 31st December	**122,070**	88,663

National Cancer Registry Ireland

National Cancer Registry Board

Draft Balance Sheet

as at 31st December 2013

	2013		2012	
	€	€	€	€
Fixed Assets		**36,208**		30,237
Current Asset				
Debtors and Prepayments	**94,906**		87,902	
Cash at bank and in hand	**664,935**		833,385	
	759,841		921,287	
Current Liabilities				
Amounts due to U.C.C.	**0**		206,159	
Revenue & Payroll Deductions	**86,480**		0	
Other Creditors	**19,789**		22,237	
Accruals	**54,151**		48,058	
Grants received in advance	**477,351**		556,170	
	637,771		832,624	
Net Current Assets		**122,070**		88,663
Total Assets Less Current Liabilities		**158,278**		118,900
Financed by:				
Capital Grants		**36,208**		30,237
Income and Expenditure Account		**122,070**		88,663
		158,278		118,900

Additional financial statements

The National Cancer Registry was fully compliant with its obligations under tax law in 2013.

The National Cancer Registry is fully adherent to Government procurement policy.

No fees are paid to members of the National Cancer Registry Board.

Attendance at Board meetings in 2013 was as follows:

	2/4/2013	22/7/2013	16/9/2013	16/12/2013
Dr Susan O'Reilly	x	x	x	x
Dr Anna Gavin	x	x	x	x
Dr Fenton Howell	x	x	x	x
Mr John McCormack	x	x	x	x
Ms Mary Jackson (to 13/10/13)	x	x	x	
Mr Michael Conroy (from 14/10/13)				x
Ms Orla Dolan (from 14/10/13)				x
Total	5	5	5	6

Aggregate expenses paid to Board members in 2012 were €175.69, as follows:

	Board meeting 2/4/2013	Audit Committee 17/5/13	Board meeting 16/12/2013	**2013 total**
Dr Susan O'Reilly	206.87			**206.87**
Dr Anna Gavin				
Dr Fenton Howell	305.32	65.77	205.42	**576.51**
Mr John McCormack				
Ms Mary Jackson (to 13/10/13)				
Mr Michael Conroy (from 14/10/13)				
Ms Orla Dolan (from 14/10/13)				
Total				**783.38**

National Cancer Registry Ireland

National Cancer Registry
Building 6800
Cork Airport Business Park
Cork
Ireland

T: +353 21 4318014
F: +353 21 4318016
E: info@ncri.ie
W: www.ncri.ie