NATIONAL CANCER REGISTRY

ANNUAL REPORT AND ACCOUNTS

FOR THE YEAR ENDING 31ST DECEMBER 2016

National Cancer Registry Ireland

CONTENTS

FOREWORD

I would like to acknowledge with gratitude the sterling contribution made by Dr. Susan O'Reilly who completed her term as Chair of the Board of the National Cancer Registry in February of this year. It is an honour to have been nominated as her successor on the Board by the Minister.

The National Cancer Registry is a critical element of cancer services in this country. It will become an increasingly important agency recording, analysing and reporting changes in cancer incidence, prevalence and survival data as the State continues to invest in cancer prevention, diagnostics and treatment. The third National Cancer Strategy will be published shortly and the Registry, having contributed to the development of the Strategy, will also have a role in implementing its recommendations.

By international standards the Registry has been hugely successful in fulfilling its statutory functions. However the increase in the number of both patients and long term survivors will generate a very large volume of additional data for the Registry to collect and analyse. To meet this challenge there is a clear opportunity to automate and facilitate data collection from hospitals by linkage to the national Medical Laboratory Information System (MedLIS), the national Medical Oncology Clinical Information (MOCIS) and other clinical datasets.

The Registry makes it's anonymised data freely available to inform clinicians, healthcare providers and external researchers. It has a highly productive and collaborative research output and this is going to expand significantly since the Dr. Clough-Gorr's appointment as director last year, creating a new Professor of Cancer Epidemiology in partnership with University College Cork.

On behalf of the board, I would like to express our appreciation of the expertise and dedication of Kerri and her staff in their ongoing commitment to high quality data capture, analysis and outputs.

Yours Sincerely,

Dr. Jerome Coffey MD FRCPI FRCR FFRRCSI
Board Chairman
June 19th, 2017

DIRECTOR'S STATEMENT

This has been a year of transition for NCRI. Dr Harry Comber officially retired after years of dedicated service as NCRI Director and Interim Director. This was also the last year of Dr Susan O'Reilly's role as Chair of the NCRI Board. Over their tenure, Drs Comber and O'Reilly worked tirelessly to ensure NCRI had an important role in cancer control in Ireland as well as a strong international reputation. We are all grateful for their efforts. It is on the foundation of their work that I have the privilege and pleasure, as NCRI Director, to guide NCRI into the future. Although here for only a few months in 2016 the transition has gone smoothly. The dedicated and first-rate NCRI staff have warmly welcomed me and eased my entry. In addition, we are delighted to welcome Dr Jerome Coffey as the new Chair of the NCRI Board.

There are certainly challenges we will need to get through to reach NCRI's full future potential. To achieve world class stature as a cancer registry will require sufficient funding from the Department of Health, additional staff to concentrate on data quality and timeliness, an emphasis on rebuilding the NCRI research program, and a strategic eye for harnessing the untapped potential of NCRI. I look forward to my first full year in 2017, the continued support of the NCRI Board and working with NCRI staff beyond the transitions.

Kerri Clough Gorr

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 reappointed by the Minister on February 15th 2016. Its members are:

- Dr Susan O'Reilly (Chair)
- Mr Michael Conroy
- Ms Orla Dolan
- Dr Anna Gavin
- Dr Fenton Howell
- Dr Catherine Kelly
- 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.

REPORT OF THE BOARD ON CORPORATE GOVERNANCE

Report of the Chairperson, National Cancer Registry Board for year ending 31/12/2016

1. Commercially significant developments affecting the body

   No commercially significant developments occurred during 2016.

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 2016.

   (iii) Policies and procedures setting out instructions for all areas of financial activity were in place for 2016. These 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 function was carried out by University College Cork in 2016. 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 in April 2013 and oversaw the work of the Internal Auditors during 2016.

   (v) An ITT for Internal Audit Services was undertaken in July 2016 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 2016 in the areas of Risk Management, Document Management and Business Continuity Planning and Disaster Recovery.

   (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 National Cancer Registry is in compliance with current procurement rules and guidelines as set out by the Office of Government Procurement.

e) The Board carried out a review of the effectiveness of Internal Financial Controls for 2016 at its meeting in February 2017.

4. Codes of business conduct for the Board 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 Board members' fees is not relevant as there are no fees paid to the Board members of 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. All appropriate requirements of the Department of Public Expenditure and Reform Public Spending Code are being complied with.
10. Procedures are in place for the making of protected disclosures in accordance with section 21(1) of the Protected Disclosures Act 2014.
11. The Code of Practice for the Governance of State Bodies (2016) has been adopted by the Board and is being fully complied with.
12. The National Cancer Registry is not involved in any legal disputes involving other State bodies.
13. There is no significant post balance sheet events.
14. 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

REPORT ON SYSTEM OF INTERNAL FINANCIAL CONTROL

Governance

Board

The National Cancer Registry Board addresses all matters outlined in the schedule of matters, as per the Code of Practice.

Briefing for new Board members

On their appointment new members are provided with 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 2016.

Internal audit function

An internal audit service is in place and is carrying out a systematic audit of all areas of Registry activity. In 2016, the following areas were audited:

- Business Continuity Planning and Disaster Recovery
- Risk Management
- Document Management

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 2016, 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 2016.

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 June 2016. 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 2013-2017, in September 2015. A Service Plan was provided to the Department of Health in February 2016 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 2016 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 met four times in 2016. 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

STAFF

The permanent staff complement on 31/12/2016 was 38 FTE. In addition, 7 FTE researchers were on specified contracts funded from external sources.

National Cancer Registry Total Headcount = 52 employees (31/12/2016)

Grade – (Permanent DoH Funded Staff)	FTE	Number	Total
Grade III	1	1	1
Grade IV	4	4	4
Grade V	8.6	10	10
Grade VI	2.26	3	3
Grade VII	2.81	4	4
Grade VIII	1	1	1
Grade – Senior Lecturer	1	1	1
Grade – State Chemist	1	1	1
Grade – Senior Staff Nurse (SSN)	5.11	7	7
Grade – Senior Staff Nurse Dual Qualified (SSN DQ)	3.71	5	5
Grade – Staff Nurse (SN)	7.5	8	8
Total	**38**	**45**	**45**
Grade – (Temporary Externally Funded Staff)			
Grade IV	4	4	4
Grade V	2	2	2
Grade VI	1	1	1
Total	7	7	7
Overall Total	**45**	**52**	**52**

ACTIVITIES

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

Data acquisition

Registration activity

Table 4.1. Number of registrations by year (December 2016)

year of incidence	open	closed	% closed	all cases	% of expected cases
2007	3	30687	100%	30690	112%
2008	9	31818	100%	31827	111%
2009	4	34096	100%	34100	113%
2010	3	35829	100%	35832	111%
2011	9	38667	100%	38676	114%
2012	8	38546	100%	38554	106%
2013	33	38811	100%	38844	103%
2014	155	39418	100%	39573	102%
2015	5723	33530	85%	39253	101%
2016	19190	7774	29%	26964	69%

The Registry database now has around 560,000 registrations (individual patients) and 678,000 tumours.
Over 39,000 cancers are now being registered annually, compared to 19,000 in 1994. Just under 45,800 new tumours have been created and 44,800 closed between January and December 2016. (This includes tumours that were both created and closed in 2016.)
The corresponding figures for 2015 were 43,500 created and 39,600 closed.

Note: the expected number of cases is estimated using the average number or registrations for the three years prior to the year of incidence that is being reported.

Timeliness

In 2014, the most recent complete year of incidence, 87% of tumours were registered within 12 months of date of incidence, an improvement of 2% from 2013 (Table 4.2). 19% of tumours were closed within a year of date of incidence which was an improvement from 17.5% in 2013. There are continuing small improvements in these figures s, but the overall picture remains much the same. Only a wholesale move to high quality electronic data, collected at the point of care, would be likely to bring about significant improvements in timeliness.

While backlogs continue to be of concern we have addressed two areas that were without cover for an extended period of time. For the next couple of years we anticipate a number of retirements which will impact on timeliness due to numerous factors, eg recruitment time lag and training of the new CDRs. It takes approximately two years for a CDR to become competent in the role.

The pending implementation of the new CRS will have an impact on timeliness of data both in the lead up to the go live date and in the follow through. This cannot be understated.

Table 4.2. Interval from date of incidence to date of case creation and closure

year of incidence	Registrations as % of expected	< 3 mths	< 6 mths	<12 mths	< 15 mths	< 24 mths	< 36 mths +
2007	108.4%	46.5%	67.1%	84.0%	87.4%	96.4%	100.0%
2008	109.9%	47.1%	67.9%	84.5%	90.0%	96.4%	100.0%
2009	109.3%	49.6%	72.4%	87.3%	91.1%	96.6%	100.0%
2010	107.2%	57.8%	73.4%	85.9%	90.2%	96.4%	100.0%
2011	107.5%	57.6%	68.6%	82.8%	90.1%	96.1%	100.0%
2012	104.1%	53.5%	64.8%	82.8%	89.0%	96.1%	100.0%
2013	103.3%	48.8%	70.6%	84.8%	91.2%	97.2%	100.0%
2014	102.8%	42.8%	69.0%	87.0%	92.1%	98.3%	*100.0%*
2015	103.9%	*55.0%*	*78.0%*	*90.3%*	*94.6%*	*99.8%*	*100.0%*
2016	94.3%	*70.7%*	*92.8%*	*99.5%*	*100.0%*	*100.0%*	*100.0%*

Figures in italics are for incomplete years

The drop in the percentage of cases created in 2013 and 2014 compared to 2010 to 2012 and to 2015 is due to illness and retirement when the Registry was unable to recruit replacements.

Table 4.3. Interval from date of incidence to date of case creation and closure

year of incidence	Registrations as % of expected	3 mths	< 6 mths	<12 mths	< 15 mths	< 24 mths	< 36 mths +
2007	108.4%	2.2%	6.9%	24.4%	33.8%	68.9%	100.0%
2008	109.9%	2.1%	6.3%	21.0%	33.6%	74.0%	100.0%
2009	109.3%	2.5%	7.8%	23.8%	34.8%	76.5%	100.0%
2010	107.2%	2.6%	8.0%	21.3%	32.4%	73.5%	100.0%
2011	107.5%	2.3%	6.9%	21.6%	33.7%	72.3%	100.0%
2012	104.1%	2.1%	7.0%	20.8%	32.5%	68.7%	100.0%
2013	103.3%	1.9%	5.9%	17.5%	30.9%	74.9%	100.0%
2014	102.8%	1.3%	4.3%	19.2%	32.2%	84.6%	*100.0%*
2015	103.9%	*1.5%*	*4.5%*	*21.9%*	*43.4%*	*97.5%*	*100.0%*
2016	94.3%	*13.4%*	*34.9%*	*83.8%*	*99.9%*	*99.9%*	*99.9%*

Figures in italics are for incomplete years

There seems to be an improvement in case closure in 2015 and will see if this is over the next few years.

Table 4.4. Interval from date of case creation to case closure

year of incidence	Registrations as % of expected	3 mths	< 6 mths	<12 mths	< 15 mths	< 24 mths	< 36 mths +
2007	108.4%	15.6%	24.3%	47.1%	61.4%	86.1%	100.0%
2008	109.9%	14.9%	23.7%	43.9%	60.6%	90.3%	100.0%
2009	109.3%	14.9%	23.6%	43.0%	59.5%	92.4%	100.0%
2010	107.2%	15.3%	24.0%	41.9%	58.6%	89.0%	100.0%
2011	107.5%	15.4%	23.2%	44.8%	60.1%	89.3%	100.0%
2012	104.1%	15.3%	21.9%	42.3%	56.2%	89.8%	100.0%
2013	103.3%	13.4%	18.5%	40.7%	60.4%	91.5%	100.0%
2014	102.8%	13.2%	21.7%	48.0%	62.8%	96.3%	*100.0%*
2015	103.9%	*14.4%*	*21.2%*	*51.9%*	*71.5%*	*99.8%*	*100.0%*
2016	94.3%	*38.8%*	*56.5%*	*99.2%*	*100.0%*	*100.0%*	*100.0%*

Figures in italics are for incomplete years

Treatment

The number of treatment episodes registered has increased from 31,400 in 1994 to just over 88,300 in 2014, the most recent complete year (Tables 4.3 and 4.4). As with case completion, completeness of treatment registration lags behind case generation. Just under 99,000 additional treatment episodes have been added in 2016.

Table 4.5. Treatments by type and year of treatment

type	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
autopsy	43	56	71	58	67	61	64	65	*52*	*12*
biopsy	19186	21497	23531	25256	27094	27261	27771	28025	*26659*	*13569*
chemotherapy	6527	7175	8029	8967	9148	9277	9182	9169	*8411*	*2591*
consultation	5900	6426	5822	6142	6926	7036	7251	7661	*6811*	*2453*
hormone	3061	3257	3396	3256	3634	3700	3586	3182	*2765*	*931*
other treatments	1502	1367	1157	914	1040	886	891	859	*542*	*111*
radiotherapy	6468	7478	7774	8385	8738	8886	8789	8732	*7620*	*2788*
surgery	22263	23195	25530	26413	28614	28799	29123	30547	*30205*	*16148*
all treatments	64953	70454	75313	79398	85268	85910	86669	88314	*86991*	*55235*

Figures in italics are for incomplete years

Table 4.6. Treatments by type and year of incidence

type	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
autopsy	47	56	71	58	69	59	61	*68*	*51*	*9*
biopsy	19365	21568	23577	25353	27226	27291	27831	*28030*	*26367*	*12823*
chemotherapy	6726	7230	8264	9207	9130	9292	9265	*9047*	*7877*	*1426*
consultation	5915	6388	5839	6293	7126	7101	7203	*7713*	*6466*	*1750*
hormone	3166	3269	3393	3312	3703	3812	3466	*3163*	*2485*	*295*
other treatments	1502	1365	1129	890	1043	863	887	*846*	*514*	*97*
radiotherapy	6709	7638	8128	8491	8974	8767	8984	*8150*	*6462*	*963*
surgery	22441	23396	25614	26851	28793	28899	29405	*30528*	*29720*	*13981*
unknown	2	8	3	10	9	5	28	*103*	*4452*	*17983*
all treatments	65873	70918	76018	80465	86073	86089	87130	*87648*	*84394*	*49327*

Figures in italics are for incomplete years

Electronic pathology data

Pathology is now being processed electronically for the following hospitals.

Cancer centres: Beaumont Hospital, Galway University Hospital, St. James's Hospital, St. Vincent's University Hospital, University Hospital Limerick (skins only).
This will be extended CUH and to all sites for UHL from April 2017.

Acute hospitals: Tallaght Hospital, Our Lady of Lourdes, Letterkenny General Hospital and Sligo General Hospital. Letterkenny went live at the end of September 2016 and Sligo at the end of March 2017.

Private hospitals: Mater Private Hospital and the Beacon Clinic.

We do not receive the full text of the pathology report from Our Lady of Lourdes, Tallaght Hospital, Mater Private, Galway University Hospital, Beaumont Hospital and the Beacon Clinic. Therefore tumours are registered with very limited information and this remains the situation until the CDR reviews or closes the tumour. This can take anything from 9 months to 24 months.
Where we do receive the full text of the report there are no resources to review the pathology reports for certain hospitals. These cases are also registered with limited information until the tumour is reviewed or closed by CDR.

Due to staff changes at a private hospital an electronic pathology extract is no longer available to the Registry. Pathology is registered to the end of September 2016. There is no date yet for the resumption of the extract.

As each pathology extract is radically different, it is important to carry out quality assurance on the data. Any outstanding issues need to be resolved before implementation of the new system; this has been a priority for 2016 and will continue to be a priority until the full implementation of the new system.

The Registry continued to work on the national MedLIS project during 2016 and has been in contact with the project team in 2017.

IT developments

Cancer Registration System

This project continued to progress during 2016. A number of cycles of user testing on the manual entry phase were completed. A number of data migration runs were completed and verified. Development was completed on electronic data phase with unit testing completed.
This project will complete in 2017.

Increased security

In 2016 the Registry implemented solutions to further protect the Registry against Malware threats. The Registry implemented Heimdal on all Registry desktops and laptops. Heimdal runs in background and checks internet traffic to detect and blocks any dubious destinations. The This product runs side-by-side with McAfee anti-virus.
In addition the Registry implemented Novi, which reviews all e-mail to the Registry before any other checks are applied. Suspect e-mail is either blocked or quarantined depending on the level of suspicion attached by Novi.

Encryption

In 2016 the Registry started a project to replace TrueCrypt with McAfee as its encryption utility. McAfee enables automatic, transparent encryption without hindering performance. Encryption is automatically deployed in accordance with the Registry's policy and can be set differently for separate individuals or groups. A central management console allows for easy and auditable management of the solution. The solution can provide proof of encryption in the event of a missing laptop or desktop.
This project will continue to completion during 2017.

Research and Dissemination

Grants awarded

- European Commission funding: "Joint Action on Rare Cancers" **€3,210** over three years.
- Health Research Board Summer Studentship award: "Analysis of a large population-based survey of women's knowledge of, and attitudes towards HPV infection and vaccination"**€2,000**.

Other awards

- None.

Summary of dissemination activities, 2016

1. Data provision for CI5, EUROCIM, EUROCARE and similar projects on time and as requested.
    - Cancer Incidence in Five Continents: dataset submitted to IARC in November 2016.

- CONCORD 3: dataset submitted in October 2016.
- SurvMark2 (International Cancer Benchmarking Partnership): dataset prepared October 2016, submission deferred to 2017 pending receipt of data transfer agreement from IARC.
- Incidence figures were updated to 2014 in December for the cancer strategy report being prepared by the Department of Health.

2. Papers submitted in 2016 and published/in press by 31/12/2016 on which National Cancer Registry staff member was first or last/senior author: **15 (**of total 25 papers with any NCR author, submitted & first published/in press in 2016)
3. Number of papers submitted in 2016 and under review at 31/12/2016 on which NCR staff member was first or last/senior author: **2** (of total 6 papers with Any NCR author)
4. Total papers first published in 2016 on which NCR staff member was a named author: **31** (of which 6 were submitted in 2014 or 2015).
5. Oral and poster presentations at national and international conferences. **6** *[plus 3 invited presentations]*
6. Number of grant/funding applications made in 2016: **2** (HRB Summer Studentship for 2017, EC Joint Action on Rare Cancer for 2016-2019).
7. Queries:
   At least **382** queries dealt with in 2016.
8. Reports
   - Number of full reports published in 2016: **2** (annual statistical report and cancer inequalities report).
   - Number of short reports published in 2016: **3** (trends reports).
9. Press release and/or website news item:
   - Total number of news items in 2016: **36**. At least one tweet per news item was made.
   - Number of press releases in 2016: **5** (including 4 for reports and 1 re appointment of new Director).
10. Registry website:
    - Updated cancer incidence figures (1994-2013) added in January.
    - The data request form and downloadable dataset were updated (to 2013 cases) in February.
    - Online maps of cancer incidence updated to 2013 in March.
    - The level of detail (small case-counts and county-level detail) available through the website was reviewed and reduced in October.

Full and short reports published in 2016

Full reports published 2016

1. Cancer inequalities in Ireland by deprivation, urban/rural status and age: a report by the National Cancer Registry. National Cancer Registry, Cork, 2016 (Walsh PM, McDevitt J, Deady S, O'Brien K, Comber H)
2. Cancer in Ireland 1994-2014: Annual report of the National Cancer Registry. National Cancer Registry, Cork, 2016 (McDevitt J, Walsh PM)

Cancer trends short reports published 2016

1. Breast cancer (McDevitt J).
2. Prostate cancer (O'Brien K).
3. Primary liver cancer (Deady S).

PAPERS WITH REGISTRY AUTHORS PUBLISHED OR IN PRESS AT 31/12/2016

1. Ali H, Sinnott S-J, Corcoran P, Deady S, Sharp L, Kabir Z. Oral cancer incidence and survival rates in the Republic of Ireland, 1994-2009. BMC Cancer. 2016.
2. Balfe M, Butow P, O'Sullivan E, Gooberman-Hill R, Timmons A, Sharp L. The financial impact of head and neck cancer caregiving: a qualitative study Psychooncology. 2016 Feb 2. [Epub ahead of print].
3. Balfe M, Keohane K, O'Brien K M, Sharp L. Social networks, social support and social negativity: A qualitative study of head and neck cancer caregivers' experiences. Eur J Cancer Care. 2016 Dec 22. [Epub ahead of print].
4. Balfe M, O'Brien KM, Timmons A, Butow P, O'Sullivan E, Gooberman-Hill R, Sharp L. Informal caregiving in head and neck cancer: caregiving activities and psychological well-being. Eur J Cancer Care. 2016 Jul 11. [Epub ahead of print].
5. Balfe, M., O'Brien, K., Timmons, A., Butow, P., O'Sullivan, E., Gooberman-Hill, R., Sharp, L. What factors are associated with posttraumatic growth in head and neck cancer carers? Eur J Oncol Nurs. 2016;21:31-37.
6. Balfe M, O'Brien KM, Timmons A, Butow P. O'Sullivan E, Gooberman-Hill R, Sharp L. The unmet supportive care needs of long-term head and neck cancer caregivers in the extended survivorship period. J Clin Nurs. 2016;25(11-12):1576 – 1586.
7. Bhatt N, Deady S, Gillis A, Bertuzzi A, Fabre A, Heffernan E, Gillham C, O'Toole G, Ridgway PF. Epidemiological study of soft-tissue sarcomas in Ireland. Cancer Med. 2016;5(1):129-35. [*Epublished 2015*.]
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9. Clarke N, Gallagher P, Kearney PM, McNamara D, Sharp L. Impact of gender on decisions to participate in faecal immunochemical test-based colorectal cancer screening: a qualitative study. Psychooncology. 2016 Feb 18. [Epub ahead of print].
10. Clarke N, McNamara D, Kearney PM, O'Morain CA, Shearer N, Sharp L. The role of area-level deprivation and gender in participation in population-based faecal immunochemical test (FIT) colorectal cancer screening. Prev Med. 2016;93:198-203.
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12. Collins DC, Velázquez-Kennedy K, Deady S, Brady AP, Sweeney P, Power DG. National incidence, management and survival of urachal carcinoma. Rare Tumors. 2016;8(3):6257.
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14. Comber H, Sharp L, de Camargo Cancela M, Haase T, Johnson H, Pratschke J. Causes and outcomes of emergency presentation of rectal cancer. Int J Cancer. 2016.
15. Drummond FJ, O'Leary E, Gavin A, Kinnear H, Sharp L. Mode of prostate cancer detection is associated with the psychological wellbeing of survivors: results from the PiCTure study. Support Care Cancer. 2016;24(5):2297-307.
16. Gaynor C, Iqbal M, Comber H, Deady S, McCormick A. Improving prognosis for patients with hepatocellular carcinoma in Ireland 1994-2008. Eur J Gastroenterol Hepatol. 2016 Nov 9. [Epub ahead of print].

17. Gogarty DS, Lennon P, Deady S, Barry O'Sullivan J, McArdle O, Leader M, Sheahan P, O'Neill JP. Variation in treatment and outcome in the early stage oral cavity squamous cell carcinoma. Eur Arch Otorhinolaryngol. 2016 Sep 9. [Epub ahead of print].
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19. Lennon P, Deady S, Healy ML, Toner M, Kinsella J, Timon CI, O'Neill JP. Anaplastic thyroid carcinoma: Failure of conventional therapy but hope of targeted therapy. Head & Neck. 2016 Feb 18. [Epub ahead of print].
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21. McDevitt J, Comber H, Walsh PM. Colorectal cancer incidence and survival by sub-site and stage of diagnosis: a population-based study at the advent of national screening. Ir J Med Sci. 2016 Nov 1. [Epub ahead of print].
22. McDevitt J, de Camargo Cancela M, Kelly M, Comber H, Sharp L. Tracheostomy and infection prolong length of stay in hospital after surgery for head and neck cancer: a population based study. Oral Surg Oral Med Oral Pathol Oral Radio. 2016;121(1):22-28.e1. [*Epublished 2015*.]
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24. O'Connor M, Gallagher P, Waller J, Martin CM, O'Leary JJ, Sharp L; Irish Cervical Screening Research Consortium (CERVIVA). Adverse psychological outcomes following colposcopy and related procedures: a systematic review. BJOG. 2016;123(1):24-38. [*Submitted 2014, Epublished 2015*.]
25. O'Connor M, O'Leary E, Waller J, Gallagher P, D'arcy T, Flannelly G, Martin CM, McRae J, Prendiville W, Ruttle C, White C, Pilkington L, O'Leary JJ, Sharp L; Irish Cervical Screening Research Consortium (CERVIVA). Trends in, and predictors of, anxiety and specific worries following colposcopy: a 12-month longitudinal study. Psychooncology. 2016;25(5):597-604. [*Epublished 2015*.]
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Invited conference/meeting presentations made by Registry staff

1. O'Brien K. Cancer registry methodologies. School of Statistics, University College Dublin, 9th November 2016.
2. Walsh PM. Cancer in the older Irish population. 2nd Irish Geriatric Oncology Meeting, Dublin, 9th April 2016.
3. Walsh PM, McDevitt J, Deady S, O'Brien K, Comber H. Cancer inequalities in Ireland by deprivation, urban/rural status and age. National Cancer Control Programme, Dublin, 9th May 2016.

Oral presentations or oral poster presentations made by Registry staff

1. Brown C, Barron T I. Caution in time-to-event models where a pre-event state modifies time-varying exposure. 2nd Annual Conference of the SPHeRE Network, Royal College of Surgeons, Dublin, 29th February 2016.
2. O'Brien K. Characteristics of screen-detected breast cancers. Conference on Applied Statistics in Ireland, University of Limerick, 16th-18th May 2016.
3. O'Connor M, O'Brien K, Waller J, Gallagher O, D'Arcy T, Flannelly G, Martin CM, Prendiville W, O'Leary JJ, Sharp L. Physical after-effects of colposcopy and their interrelationships with psychological distress: a longitudinal study. 18th International Psycho Oncology Society Congress, Dublin, 17th-21st October 2016.
4. O'Connor M, Waller J, Gallagher P, Martin C, O'Leary J, Sharp L. Development of a theory-based intervention to alleviate psychological distress of follow-up procedures for cervical abnormalities. UK Society for Behavioural Medicine 12th Annual Scientific Meeting, Cardiff, 1st-2nd December 2016.

Poster presentations made by Registry staff

1. O'Connor M, O'Brien K, McRae J, Martin CM, O'Leary JJ, Sharp L. What can we do to increase cervical cancer screening uptake among older women? Understanding the views of older women. 18th International Psycho Oncology Society Congress, Dublin, 17th-21st October 2016. to 21 Oct 2016
2. Pearce AM, Watson V, Gallagher P, Timmons A, Sharp L. Pre-testing with cognitive interviews highlights unanticipated decision making in a DCE. Health Economics Study Group Meeting Winter 2016, Manchester, 6th-8th January 2016.

Research

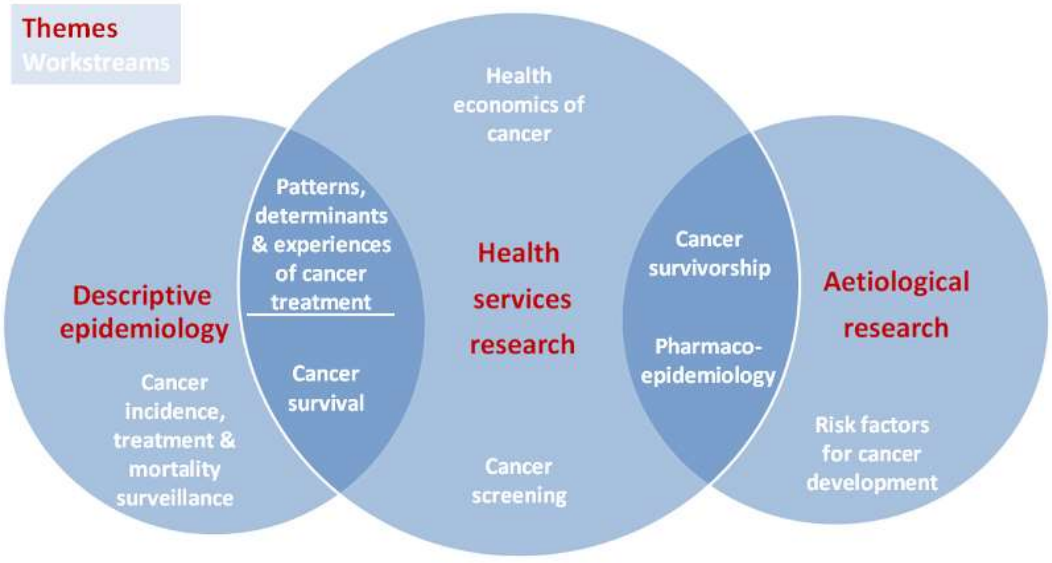
Aims

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 projects

A core aim of the National Cancer Registry, Ireland is to promote and facilitate the use of our data in research and in the planning and management of cancer services in Ireland. In addition, we have research interests and expertise in a broad range of cancer-related topics outside of the use of cancer registration data. As such we have developed a diverse portfolio of research projects, many of which involve collaboration both within and outside the National Cancer Registry. 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:

- 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.

A list of current projects is given below.

Project title	Research theme
ATHENS - A Trial of HPV Education and Support	Health services research
Breast cancer subtypes: a comparison of cancers that are screen-detected, intervals, and in non-attenders	Descriptive epidemiology, Health services research
Cancer incidence in Irish kidney transplant recipients	Descriptive epidemiology, Aetiological research
Cancer incidence, treatment and mortality surveillance	Descriptive epidemiology
Cancer survival studies	Descriptive epidemiology, Health services research
CANWON - EU Cancer and Work Network	Health services research, Aetiological research

CaPPE - Cancer Pharmacoepidemiology & Pharmacoeconomics	Health services research, Aetiological research
CaRE - Cancer and Return to Employment	Health services research, Aetiological research
CERVIVA - Irish Cervical Screening Research Consortium	Health services research
CERVIVA 2 - Irish Cervical Screening Research Consortium	Health services research
CERVIVA ICE - Irish Cervical Screening Research Consortium	Health services research
CERVIVA ICE II – From episodic care to disease prevention and management: Developing analytical skills and interdisciplinary learning from the case of HPV related cancers	Health services research
Challenges in cancer survivorship - costs, inequalities and post-treatment follow-up (ICE Project)	Health services research, Aetiological research
Childhood and adolescent cancer survival and incidence	Descriptive epidemiology
CONCORD-2 – international cancer survival comparisons	Descriptive epidemiology
Consistency, appropriateness and management of cancer services	Descriptive epidemiology, Health services research
Cost-effectiveness of PSA testing for the secondary prevention of prostate cancer	Health services research
Costs of lost productivity due to cancer-related premature mortality	Health services research
Economic impact of cancer in Ireland	Health services research, Aetiological research
Effect of social and spatial isolation among cancer patients on treatment receipt and survival	Descriptive epidemiology
Effects of pharmacological exposure on Ovarian Cancer	Health services research, Aetiological research
EU Pancreas - An integrated European platform for pancreas cancer research	Aetiological research
Excess burden of cancer in men in Ireland 1994-2008	Descriptive epidemiology, Health services research
Factors associated with participation in colorectal cancer screening	Health services research
Financial impact of a cancer diagnosis	Health services research, Aetiological research
FINBAR - Factors INfluencing the Barrett's/Adenocarcinoma Relationship	Aetiological research
Geographical studies	Descriptive epidemiology
Hospital length-of-stay after cancer surgery	Descriptive epidemiology, Health services research
International comparisons of breast cancer treatment and survival	Descriptive epidemiology, Health services research
PanCAM - Pancreatic Cancer Aetiology & Management	Health services research, Aetiological research

PiCTure - Prostate Cancer Treatment: the effect on health-related quality-of-life and other patient-reported outcomes	Health services research, Aetiological research
PiCTure 2 - Men's experiences of prostate cancer care in Ireland	Health services research
Smoking & survival in cancer	Descriptive epidemiology, Health services research
SuN study - supportive care needs of survivors of head & neck cancer	Health services research, Aetiological research
SuN Study 2 - supportive care needs of informal carers of survivors of head & neck cancer	Health services research, Aetiological research
TReat - Treatment Receipt in Elderly women diagnosed with cancer	Descriptive epidemiology, Health services research

Grant/funding applications submitted in 2015

Applications made in 2015 for which final decision was pending at year end

Drummond F, O'Brien K et al. Investigation of the feasibility of screening for psychological distress 'the sixth vital sign in cancer care' among men with prostate cancer; Towards improved cancer care and survivorship. Health Research Board Health Research Awards 2015. [*Unsuccessful*.]

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

Performance indicators

a. Timeliness	**2012**	**2013**
1. 50% of invasive cancers, excluding non-melanoma skin, should be registered within 3 months of the date of incidence.	53.6%	49%
2. 90% of invasive cancers, excluding non-melanoma skin, should be registered within 12 months of the date of incidence.	82.9%	85.2%
3. 90% of invasive cancers, excluding non-melanoma skin, should be closed within 24 months of the date of incidence.	68.9%	75.6%
b. Accuracy		
1. Death certificate only cases should be <1% of the total of all invasive cancers, excluding non-melanoma skin.	0.5%	1%
2. 90% of all invasive cancers, excluding non-melanoma skin, should be microscopically verified, if the case is closed.	92.4%	92.4%
3. Cancers of ill-defined sites should be less than 3% of all invasive cancers, excluding non-melanoma skin.	2.0%	2.0%

Research and Dissemination

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

- Cancer Strategy review – further data and analyses provided to Department of Health on incidence, trends, projections, prevalence, survival, staging, radiotherapy, adolescent cancers and cancer inequities.

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.

- Papers submitted in 2016 and published/in press by 31/12/2016 on which National Cancer Registry staff member was first or last/senior author: **15** (of total 25 papers with NCR author, submitted & first published/in press in 2016).
- Number of papers submitted in 2016 and under review at 31/12/2016 on which NCR staff member was first or last/senior author: **2** (of total 6 papers with any NCR author)

(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 2015: **25**

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

- Number of grant/funding applications made in 2016: **2** (HRB Summer Studentship for 2017, EC Joint Action on Rare Cancers for 2016-2019).

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

- **382** queries dealt with in 2016; 93% replied to within 2 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 2016: **2** (annual statistical report and cancer inequalities report).
- Number of short reports published in 2015: **3** (trend reports)

Administration

1. The annual accounts and report of the Board to be produced by June 30th
   - Yes
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
   - Yes. All audit recommendations were closed out within agreed timeframes.

OVERVIEW OF ENERGY USAGE IN 2016

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 2016, the National Cancer Registry consumed 75.3 MWh of energy, all electrical.

Actions Undertaken in 2016

In 2016 the Registry undertook a range of initiatives to improve our energy performance, including:

- Implementing a virtualisation project in the server room, decommissioning six servers which resulted in large savings in energy usage;
- 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.

Comptroller and Auditor General

Report for presentation to the Houses of the Oireachtas

National Cancer Registry Board

I have audited the financial statements of the National Cancer Registry Board for the year ended 31 December 2016 under Section 5 of the Comptroller and Auditor General (Amendment) Act 1993. The financial statements comprise the statement of income and expenditure and retained revenue reserves, the statement of financial position, the statement of cash flows and the related notes. The financial statements have been prepared in the form prescribed under Section 21 of the National Cancer Registry Board (Establishment) Order 1991 and in accordance with generally accepted accounting practice as modified by the Minister for Health in relation to accounting for superannuation costs.

Responsibilities of the Members of the Board

The Board is responsible for the preparation of the financial statements, for ensuring that they give a true and fair view and for ensuring the regularity of transactions.

Responsibilities of the Comptroller and Auditor General

My responsibility is to audit the financial statements and to report on them in accordance with applicable law.

My audit is conducted by reference to the special considerations which attach to State bodies in relation to their management and operation.

My audit is carried out in accordance with the International Standards on Auditing (UK and Ireland) and in compliance with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements, sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of

- whether the accounting policies are appropriate to the Board's circumstances, and have been consistently applied and adequately disclosed
- the reasonableness of significant accounting estimates made in the preparation of the financial statements, and
- the overall presentation of the financial statements.

I also seek to obtain evidence about the regularity of financial transactions in the course of audit.

In addition, I read the Board's annual report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by me in the course of performing the audit. If I become aware of any apparent material misstatements or inconsistencies, I consider the implications for my report.

Opinion on the financial statements

In compliance with the directions of the Minister for Health, the Board accounts for the costs of superannuation entitlements only as they become payable. This basis of accounting does not comply with Financial Reporting Standard 102 which requires such costs to be recognised in the year the entitlements are earned.

In my opinion, except for the accounting treatment of the Board's superannuation costs and liabilities, the financial statements, have been properly prepared in accordance with generally accepted accounting practice in Ireland and give a true and fair view of the state of the Board's affairs at 31 December 2016 and of its income and expenditure for 2016.

In my opinion, the accounting records of the Board were sufficient to permit the financial statements to be readily and properly audited. The financial statements are in agreement with the accounting records.

Matters on which I report by exception

I report by exception if I have not received all the information and explanations I required for my audit, or if I find

- any material instance where money has not been applied for the purposes intended or where the transactions did not conform to the authorities governing them, or
- the information given in the Board's annual report is not consistent with the related financial statements or with the knowledge acquired by me in the course of performing the audit, or
- the statement on internal financial control does not reflect the Board's compliance with the Code of Practice for the Governance of State Bodies, or
- there are other material matters relating to the manner in which public business has been conducted.

I have nothing to report in regard to those matters upon which reporting is by exception.

John Crean
For and on behalf of the
Comptroller and Auditor General
22 June 2017

National Cancer Registry Board

Financial Statements for

for the year ended 31st December 2016

National Cancer Registry Board

Contents

National Cancer Registry Board

Information

Current Board

Name	Date Re-Appointed
Dr Susan O'Reilly (Chairperson)	15th February 2016
Dr Anna Gavin	15th February 2016
Dr Fenton Howell	15th February 2016
Mr John McCormack	15th February 2016
Mr Michael Conroy	15th February 2016
Ms Orla Dolan	15th February 2016
Dr Cathy Kelly	15th February 2016
Dr Jerome Coffey (Chairperson from)	31st May 2017

Director	Dr Harry Comber	Retired on 31st July 2016
	Prof. Kerri Clough Gorr	Appointed 1st August 2016

Business Address

Building 6800, Cork Airport Business Park,
Kinsale Road,
Cork.

Auditor

Comptroller and Auditor General,
3A Mayor Street
Dublin

Bankers

Allied Irish Banks plc,
66 South Mall,
Cork.

National Cancer Registry Board

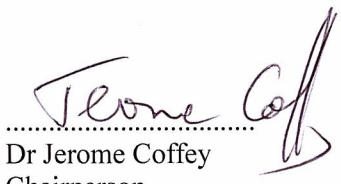
Statement of Board Members' Responsibilities

The members of the Board are required by the National Cancer Registry Board (Establishment) Order 1991, to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Board and of its Income and Expenditure for that period. In preparing those financial statements the Board is required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- comply with applicable Accounting Standards, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is appropriate to presume that the Board will not continue in operation.

The Board is responsible for keeping adequate accounting records which disclose with reasonable accuracy at any time the financial position of the National Cancer Registry Board and to enable it to ensure that the financial statements comply with the Order. It is also responsible for safeguarding the assets of the National Cancer Registry Board and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

On behalf of the Board



Dr Jerome Coffey
Chairperson

Date: 19th June 2017

Dr Fenton Howell
Board Member

Date: 15th June 2017

National Cancer Registry Board

Statement on Internal Financial Control for the year ended 31st December 2016

Responsibilities

On behalf of the Board of the National Cancer Registry, I acknowledge our responsibility for ensuring that an effective system of internal financial control is maintained and operated.

The system can only provide reasonable and not absolute assurance that assets are safeguarded, transactions authorised and properly recorded, and that material errors or irregularities are either prevented or would be detected in a timely period.

Key Control Procedures

The key control procedures put in place designed to provide effective financial control are:

- A clearly defined management structure.
- A risk register was compiled in 2010 and was updated throughout 2016.
- A procedures document setting out instructions for all areas of financial activity was in place for 2016. 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 was carried out by University College Cork in 2016.
- The Audit Committee met on 4 occasions in 2016 and reviewed the work of the Internal Audit which is contracted out for 2016 to a private firm of Accountants
- Internal audits were carried out in 2016 in the areas of Business Continuity Planning and Disaster Recovery, Risk Management and a full Follow Up Audit for the 2013 to 2016 audit cycle. The Board formally agreed that they were satisfied with the system of internal financial controls within the Registry at their meeting on 14th February 2017.
- 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.
- Review by the Board at each of its meetings of periodic and annual financial reports.

Review of Internal Controls

I confirm that the Board carried out a review of the effectiveness of internal financial controls for 2016 at its meeting on 14th February 2017.

Signed on behalf of the Board of the National Cancer Registry

Jerome Coffey

Date: 19th June 2017

Dr Jerome Coffey
Chairperson

National Cancer Registry Board

Report of the Comptroller & Auditor General

National Cancer Registry Board

Statement of Income and Expenditure and Retained Revenue Reserves for the year ended 31st December 2016

	Notes	2016 €	2015 €
Income			
Department of Health	2	**2,734,405**	2,662,804
Retirement benefit contributions		**77,787**	98,646
Other Income	3	**480,308**	625,039
		3,292,500	3,386,489
Transfer (to)/from capital account	9	**21,766**	(115,208)
Total Income		**3,314,266**	3,271,281
Expenditure			
Staff costs	4	**2,484,524**	2,584,847
Administration costs	5	**698,517**	677,771
Travel and subsistence		**55,331**	53,256
Total Expenditure		**3,238,372**	3,315,874
Surplus/(Deficit) for year		**75,894**	(44,593)
Balance Brought Forward 1st January		**12,620**	57,213
Balance Carried Forward 31st December		**88,514**	12,620

The Statement of Cash Flows on page 7 and notes on pages 8-18 form part of these financial statements

On behalf of the Board:

.....
Dr Jerome Coffey
Chairperson

Date: 19th June 2017

.....
Dr Fenton Howell
Board Member

Date: 15th June 2017

National Cancer Registry Board

Statement of Financial Position as at 31st December 2016

	Notes	2016 €	2016 €	2015 €	2015 €
Property, Plant and Equipment	6		**177,594**		199,360
Current Asset					
Receivables and Prepayments	7	**138,422**		219,897	
Cash and Cash Equivalents		**375,731**		354,780	
		514,153		574,677	
Current Liabilities					
Revenue & Payroll Deductions		**66,497**		71,561	
Other Payables		**10,460**		15,725	
Accruals		**77,760**		129,419	
Grants received in advance	8	**270,922**		345,352	
		425,639		562,057	
Net Current Assets			**88,514**		12,620
Total Assets Less Current Liabilities			**266,108**		211,980,
Representing:					
Capital Account	9		**177,594**		199,360
Income and Expenditure Account			**88,514**		12,620
			266,108		211,980

The Statement of Cash Flows on page 7 and notes on pages 8-18 form part of these financial statements

On behalf of the Board:

Jerome Coffey

Dr Jerome Coffey
Chairperson

Date: 19th June 2017

Fenton Howell

Dr Fenton Howell
Board Member

Date: 15th June 2017

National Cancer Registry Board

Statement of Cash Flows

Reconciliation of Surplus/(Deficit) for the year to net cash inflow

	2016	2015
Net Cash Flows from Operating Activities		
Excess Income over Expenditure	**75,894**	(44,593)
Depreciation and Impairment of Fixed Assets	**142,171**	109,094
Transfer from Capital Account	**(21,766)**	115,208
(Increase)/Decrease in Receivables	**81,475**	(43,068)
Increase/(Decrease) in payables	**(136,418)**	(112,873)
Net Cash Outflow from Operation Activities	**141,356**	23,768
Cash Flows from Investing Activities		
Payments to acquire Property, Plant & Equipment	**(120,405)**	(224,302)
Net Cash Flows from Financing Activities	**0**	0
Net Increase /(Decrease) in Cash and Cash Equivalents	**20,951**	(200,534)
Cash and cash equivalents at 1 January 2016	**354,780**	555,314
Cash and cash equivalents at 31st December 2016	**375,731**	354,780

National Cancer Registry Board

Notes to the Accounts
for the year ended 31st December 2016

1. Accounting Policies

The basis of accounting and significant accounting policies adopted by the National Cancer Registry are set out below. They have all been applied consistently throughout the year and for the preceding year.

a) General Information

The National Cancer Registry was set up under the National Cancer Registry (Establishment) Order 1991 with a head office at Building 6800, Cork Airport Business Park, Kinsale Road, Cork.

The National Cancer Registry Board was established by the Minister for Health in 1991 by Statutory Instrument. It was set up to record information on all cancer cases occurring in Ireland and has been collecting such data since 1994.

Its functions were laid down in legislation in 1991, with an amendment in 1996 and are as follows:

- 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 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.

NCR is a Public Benefit Entity (PBE).

b) Statement of Compliance

The financial statements of NCR for the year ended 31 December 2016 have been prepared in accordance with FRS 102 (the financial reporting standard applicable in the UK and Ireland) as modified by the directions of the Minister in relation to superannuation. In compliance with the directions of the Minister for Health, the Board accounts for the costs of superannuation entitlements only as they become payable. (See Accounting policy (i)).
This basis of accounting does not comply with Financial Reporting Standard 102 which requires such costs to be recognised in the year the entitlements are earned.

c) Basis of Preparation

The financial statements are prepared under the accruals method of accounting and under the historical cost convention in the form approved by the Minister for Health with the concurrence of the Minister for Public Expenditure and Reform, in accordance with Section 21 of National Cancer Registry (Establishment) Order 1991. The following accounting policies have been applied consistently in dealing with items which are considered material in relation to NCR's financial statements.

d) Revenue

Oireachtas Grants

Revenue Grants are recognised on a cash receipts basis. Capital grants are transferred to a Capital Account and amortised over the same period as the related fixed assets are depreciated.

e) Research Grants

Research grants are recognised in the period in which the corresponding expenditure is incurred and are accounted for as Other Income.

f) Property, Plant & Equipment

Property, plant and equipment is stated at cost less accumulated depreciation, adjusted for any provision for impairment. Depreciation is provided on all property, plant and equipment, other than freehold land and artwork, at rates estimated to write off the cost less the estimated residual value of each asset on a straight line basis over their estimated useful lives, as follows:

(i) Fixtures and Fittings	20% per annum
(ii) Office Equipment	20% per annum
(iii) Computer Hardware	25% per annum
(iv) Computer Software	33% per annum

Residual value represents the estimated amount which would currently be obtained from disposal of an asset, after deducting estimated costs of disposal, if the asset were already of an age and in the condition expected at the end of its useful life.

If there is objective evidence of impairment of the value of an asset, an impairment loss is recognised in the Statement of Income and Expenditure and Retained Revenue Reserves in the year.

g) Operating Leases

Rental expenditure under operating leases is recognised in the Statement of Income and Expenditure and Retained Revenue Reserves over the life of the lease.

h) Employee Benefits

Short-term Benefits

Short term benefits such as holiday pay are recognised as an expense in the year, and benefits that are accrued at year-end are included in the Payables figure in the Statement of Financial Position.

i) Retirement Benefits

By direction of the Minister for Health no provision has been made in respect of accrued benefits payable in future years under the Nominated Health Agencies Superannuation Scheme and its Spouses and Children Scheme. Contributions from employees who are members of the scheme are credited to the Income and Expenditure account when received. Retirement Benefit payments are charged to the Income and Expenditure account when paid.

All new entrants to the public sector with effect from 1st January 2013 are members of the Single Public Sector Pension Scheme, where all employees' pension deductions are paid over to the Department of Public Expenditure and Reform. Pension payments under the scheme are charged to the statement of income and expenditure and retained revenue reserves when paid. By direction of the Minister for Health no provision has been made in respect of benefits payable in future years.

j) Critical Accounting Judgements and Estimates

The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the balance sheet date and the amounts reported for revenues and expenses during the year. However, the nature of estimation means that actual outcomes could differ from those estimates. The following judgements have had the most significant effect on amounts recognised in the financial statements.

Depreciation and Residual Values

The Directors have reviewed the asset lives and associated residual values of all fixed asset classes, and in particular, the useful economic life and residual values of fixtures and fittings, and have concluded that asset lives and residual values are appropriate.

National Cancer Registry Board

Notes to the Accounts
for the year ended 31st December 2016

2. Department of Health

	2016	2015
	€	€
Revenue Grant (Vote 38, Subhead B1)	**2,614,000**	2,440,000
Capital Grant (Note 9)	**120,405**	222,804
	2,734,405	2,662,804

3. Other Income

	2016	2015
	€	€
Research Grants		
Prostate Charity 2 (NICR)	**0**	33,838
CARG (HRB)	**81,778**	80,377
PSA Grant (HRB)	**1,873**	1,393
Bowelfit(UCC)	**1,449**	1,784
Head & Neck Extension (HRB)	**0**	542
Cancer in Older Women Grant (HRB)	**0**	136
Employment Outcomes Grant (HRB)	**0**	11
Eurocourse (EU)	**0**	619
Head & Neck Cancer Grant (HRB)	**0**	20,950
IPCOR (MMI)	**155,018**	30,776
Sanofi Grant (Sanofi Aventis)	**0**	2,435
Prostate Charity (NICR)	**2,697**	545
Rarecare (EU)	**0**	250
Ovarian Pharmacoepi (HRB)	**29,156**	132,350
Survivorship Interdisciplinary Capacity Enhancement (HRB)	**96,330**	186,165
ICS Head & Neck (ICS)	**8,706**	22,991
Cerviva Interdisciplinary Capacity Enhancement (HRB)	**0**	38,539
PSA Extension (HRB)	**0**	2,274
Eurochip funding (EU)	**0**	2,685
Pharmacoepi ICE (HRB)	**18,311**	29,637
Rarecare Net (EU)	**0**	42
Cerviva ICE 2 (HRB)	**54,004**	22,703
Blood Cancer Network (BCNI)	**11,359**	350
Equality Childhood Cancer (ICS)	**14,536**	11,200
	475,217	622,592
Non-Research Grant		
Miscellaneous	**5,091**	2,397
Sale of Fixed Assets	**0**	50
	5,091	2,447
	480,308	625,039

Grant Donors are:
Health Research Board (HRB), Health Information Quality Authority (HIQA), European Union (EU), Carlow Institute of technology (CIT), Northern Ireland Cancer Registry (NICR), Molecular Medicine Ireland (MMI), Blood Cancer Network Ireland (BCNI)

4. Information on Employees and Remuneration

	2016 Number	2015 Number
The average numbers of employees during the year was:		
Director	**1**	1
Administration	**32**	32
Cancer Data Registrar	**20**	19
	53	52

Employment Costs	2016 €	2015 €
Wages and salaries	**2,152,514**	2,148,787
Social Insurance Costs	**216,716**	208,956
Retirement Benefits	**115,294**	227,104
	2,484,524	2,584,847

WTE Breakdown by salary band at end December	2016	2015
Less than €60K	**34**	32
Between €60K - €70K	**2**	2
Between €70K - €80K	**0**	0
Between €80K - €90K	**1**	1
Between €90K - €100K	**0**	0
Between €100K - €110K	**1**	1
Total	**38**	**36**

Notes to the Accounts
for the year ended 31st December 2016

Director's Remuneration (excl ERS PRSI)	**96,326**	64,374
Directors Expenses	**2,006**	2,218

The Interim Director retired on 31st July 2016 and the new Director commenced on 1st August 2016. The Interim Directors remuneration from 1st January 2016 to 31st July 2016 was € 53,175 (this includes €4,653 in respect of holidays due but not taken during the period). He was a member of the Nominated Health Agencies Superannuation Scheme and did not receive any Performance Related Award in 2016. The Directors remuneration from 1st August 2016 to 31st December 2016 was €43,151. She is a member of the Single Public Service Pension Scheme and did not receive any Performance Related Reward in 2016.

Board Members Remuneration and Expenses	**2016** €	2015 €
Travel & Subsistence to attend Board Meetings	0	184

Board members do not receive fees.

Notes to the Accounts
for the year ended 31st December 2016

5. Administration Expenses

	2016 €	2015 €
Office Consumables	**10,090**	9,873
Courier and delivery charges	**527**	438
Books and periodicals	**82**	200
C&AG Audit fee	**8,500**	8,700
Other Audit fees	**9,395**	7,380
Recruitment	**13,891**	26,061
Training & Conference fees	**44,042**	57,129
Rent & service charges	**131,843**	130,978
Insurance	**8,912**	9,932
Building repairs & maintenance	**1,624**	104
Light and heat	**11,605**	14,846
Licences, Subscriptions & Support	**93,894**	99,953
Printing, postage and stationery	**13,103**	16,532
Telephone, fax and Internet	**44,015**	47,824
Legal and professional fees	**2,460**	4,950
Bank Charges	**550**	560
Sundry expenses	**23,849**	17,035
Research Collaborations	**84,132**	109,397
Cancer Benchmarking Project	**47,323**	0
Information Technology Consumables	**6,509**	6,785
Depreciation on computer equipment	**139,498**	104,570
Depreciation on fixtures and fittings	**2,206**	4,210
Depreciation on office equipment	**467**	314
Total Administrative Expenses	**698,517**	677,771

Notes to the Accounts
for the year ended 31st December 2016

6. Property, Plant and Equipment

	Computer Equipment	Fixtures & Fittings	Office Equipment	Total
	€	€	€	€
Cost				
At 1st January 2016	693,800	312,748	19,919	1,026,467
Additions	118,067	0	2,337	120,405
Disposals	(1,857)	(1,037)	0	(2,894)
At 31st December 2016	**810,010**	**311,711**	**22,256**	**1,143,978**
Depreciation				
At 1st January 2016	500,338	306,850	19,919	827,107
On disposals	(1,857)	(1,037)	0	(2,894)
Charge for the year	139,498	2,206	467	142,171
At 31st December 2016	**637,979**	**308,019**	**20,386**	**966,384**
Net book Values				
At 31st December 2016	**172,031**	**3,692**	**1,870**	**177,594**
At 31st December 2015	193,462	5,898	0,	199,360

7. Receivables

	2016	2015
	€	€
Receivables – Research Grants (Note 8)	**31,188**	133,104
Receivables – Other	**933**	7,387
Prepayments	**106,301**	79,406
	138,422	219,897

Notes to the Accounts
for the year ended 31st December 2016

8. Grants Received in Advance/Arrears

Project (Donor)	Opening at 1st January	Income Received	T/F to I&E A/C	Closing at 31st December
Grants Currently in Advance	€	€	€	€
Pharmacoepi ICE (HRB)	19,659	0	18,311	1,348
Head and Neck (HRB)	532	0	0	532
Ovarian Pharmacoepi	58,813	0	29,156	29,657
Survivorship ICE (HRB)	201,101	0	96,330	104,771
Rarecare Net (EU)	4,520	0	0	4,520
Head & Neck 2nd Phase (HRB)	1,559	0	0	1,559
CARG (HRB)	38,871	72,990	81,778	30,083
Prostate Specific Ant(PSA) (HRB)	1,873	0	1,873	0
IPCOR (MMI)	15,728	231,841	155,018	92,551
Prostate Charity (NICR)	2,697	0	2,697	0
Joint Action Rare Cancers(EU)	0	963	0	963
Cerviva ICE (HRB)	(58,988)	63,925	0	4,937
ICS Equality Childhood (ICS)	(11,201)	25,737	14,536	0
				270,922
Grants Currently in Arrears				
Cerviva Randomised Control (HRB)	0	0	0	0
Mens Experiences (HRB)	(14,997)	14,997	0	0
ICS Head & Neck (ICS)	(22,991)	25,360	8,706	(6,337)
Cerviva ICE 2 (HRB)	(22,703)	63,565	54,004	(13,142)
Blood Cancer Network (NUIG)	(350)	0	11,359	(11,709)
Bowelfit (UCC)	(1,874)	3,323	1,449	0
				(31, 188)
Total	212,248	502,702	475,217	239,734

Research Grant Donors are:

Health Research Board (HRB)
European Union (EU)
Health Information Quality (HIQA)
Northern Ireland Cancer Registry (NICR)
Irish Cancer Society (ICS)
University College Cork (UCC)
Womens Health Council (WHC)
Molecular Medicine Ireland (MMI)

9. Capital Account	2016 Total €	2015 Total €
Balance at 1st January 2016	**199,360**	84,152
Transfer to/(from) Income and Expenditure account		
Revenue funds allocated to acquire fixed assets (Vote 38 subhead B1)	0	0
Capital Grants Received from Department of Health (Vote 38 subhead L1)	**120,405**	222,804
Capital Funds allocated to acquire fixed assets (HRB Grant)	**0**	1,498
Amount amortisation in line with asset depreciation	**(142,171)**	(109,094)
	(21,776)	115,208
Balance at 31st December 2016	**177,594**	199,360

10. Operating Lease Rentals

The Board carried out its business from a premises at Cork Airport Business Park, which it holds under a 5 year lease due to expire on 30th November 2017.

	2016	2015
Lease Rentals Charged to Income & Expenditure Account	**98,400**	98,400
The Board has the following commitments under operating leases which expire:		
Within one year	**90,200**	98,400
Within two to five years	**0**	90,200

Notes to the Accounts
for the year ended 31st December 2016

11. Pension Related Deduction

In accordance with the Financial Emergency Measures in the Public Interest Act 2009, a pension related deduction for public servants became effective from 1 March 2009. The deduction was collected and remitted on a monthly basis by the National Cancer Registry. The total of the monthly payments remitted to the Department of Health for the period from January to December 2016 was €77,085. The comparative amount for 2015 was € 107,042.

12. Related Party Transactions.

Key Management Personnel Compensation
Key Management Personnel comprises the Director and the Senior Management Team.
The total remuneration for 2016 was € 460,310 (Incl Employers PRSI).
The comparative figure for 2015 was € 414,881 (Incl Employers PRSI).

Note 4 contains a breakdown of Board fees/Expenses/ Directors Remuneration.

13. Capital Commitments.

A contract to provide a new Cancer Registration System, was commenced in 2013.
The value of the contract was € 510,450 (Incl VAT). To date € 255,223 has been spent with € 255,227 remaining. The system will go live in the summer of 2017 and the contract will be fully completed in 2017.

14. Approval of Financial Statements

The Board approved the financial statements on 14th February 2017.