N. IRELAND Cancer Registry

Operational Plan 2016-17

N. Ireland Cancer Registry

Providing information on Cancer for Research, Planning, Service Monitoring and Education

Queen's University Belfast

Contents

Executive Summary

This operational plan sets out the role, direction and priorities of the N. Ireland Cancer Registry (NICR) from April 2016 – March 2017. It also includes an overview of the Registry's achievements April 2015 - March 2016 (Appendix A). It holds to the vision, purpose and values set out in the 5-Year Strategic Plan (April 2013 – March 2018).

Our Vision: *To continually improve Intelligence on Cancer in N. Ireland.*

Our Purpose: *To provide accurate, timely information on cancers and pre-malignant disease, occurring in the population of Northern Ireland for research, education, service monitoring and service planning.*

Our Values: to

- *ensure high quality data with complete ascertainment of cases,*
- *protect the confidentiality of the data we hold,*
- *work with all who aim to reduce the cancer burden in our society,*
- *work together as a team,*
- *value and develop our staff,*
- *include patients and their representatives,*
- *provide value for money.*

2015/2016 was a very successful year for the N. Ireland Cancer Registry:

- Registry staff were instrumental in achieving legislation through the Health and Social Care (Control of Data Processing) Act which achieved Royal Assent on 11 April 2016. This will be a major benefit to the public health, academic and medical research community in Northern Ireland and removes a barrier for inclusion of Northern Ireland datasets into national audits.

- Our indicators of data quality have been measured against registries in Scotland, England, Wales and Republic of Ireland and our staging topped the leader board at 80%, a marked improvement from 70% the previous year. Other indicators e.g. death certificate only registrations, percentage microscopically verified indicated a registry of high quality. This came about despite increased numbers of cancers and increased number of data items checked and registered per case because of increased efficiencies of the Registry.

- We negotiated access to new datasets e.g. Labcentre, screening histories for bowel and cervical cancers, pathology data from private laboratories and enhanced

radiotherapy data. We have more complete data items on staging, tumour grade/ differentiation, recurrences, and screening histories. As a result we are always mindful of data governance issues and have revised agreements with Ethics, Trusts and the Quality Assurance Reference Centre (QARC). We have secure data transfer with new encrypted email facilities and hscni.net & nhs.net.

- We hosted a very successful cancer outcomes conference attended by over 600 delegates from the UK, Ireland, mainland Europe and New Zealand.

- Factsheets for 18 cancer sites, all available on the NICR website received favourable comments from users, especially clinicians. These will be updated annually by the Registry after the production of the official statistics on incidence, survival and prevalence of cancer.

- Infographics and data visualisation have also been enhanced. These materials provide user-friendly presentation of cancer statistics. Nevertheless we received 103 information requests, all answered within target timescales. With easy access to routine data these requests have become more complex.

- We continue to meet the demands of increased numbers of registrations, 40% in past 20 years, 60% increase predicted from 2015-2025.

- Registry data and our staff were involved in 17 peer reviewed publications and three reports since January 2015.

The N. Ireland Cancer Registry provided data for:

Service use:

a) The clinical genetics service and 238 requests for information.
b) A local cancer intelligence tool launched by Macmillan Cancer Support. http://lcini.macmillan.org.uk/
c) Cancer Research UK for the UK cancer statistics on their webpage.
d) Provision of data for national/international projects; Cancer Incidence in V Continents, Eurocare, UK Cancer Survival Project, London School of Hygiene and Tropical Medicine (LSHTM), NCIN National Cancer Dataset Repository, UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS), Local Cancer Intelligence Commissioning Tool, Northern Ireland Neighbourhood Information Service (NINIS) and Prevalence Projections for the UK.

Research Projects:

a) The International Cancer Benchmarking Partnership – module 4 and module 5 which has enabled NICR to access comorbidity data (funded by PHA, Macmillan and GAIN).
b) Investigating Primary Care Influences on Late Lung or Colorectal Cancer Diagnosis – targets early diagnosis interventions (funded by CRUK/NAEDI).
c) Life After Prostate Cancer – a UK wide survey of patient reported outcomes (funded by Prostate Cancer UK/Movember).
d) The value of adjuvant radiotherapy on survival and recurrence in triple negative breast cancer: an international pooled meta-analysis.
e) Commonly prescribed drugs and their association with cancer progression: a data linkage study (breast, colorectal, lung, prostate, ovarian, oesophageal and stomach cancer).
f) Study of clinical management and outcomes of pT1 staged colorectal cancer.
g) 3 Population-based studies of molecular pathology epidemiology biomarkers for colon cancer survival.
h) Beta-adrenergic receptor expression and beta-blocker use: association with breast cancer survival and prognosis.

We also continue to register Pre-malignant diseases on a population basis:

a) NI Barrett's register.
b) NI Colorectal polyp register.
c) NI Endometrial hyperplasia register.
d) NI MGUS (Monoclonal Gammopathy of Unknown Significance) register.
e) Prostate Specific Antigen (however due to lack of resources this database has not been updated for several years.

Audits:

a) We produced an audit of care received by female breast cancer patients diagnosed in 2012. This illustrated a great improvement in services with 99.8% of patients now discussed at MDTs, with service centralisation and treatments according to NICE guidelines and approved survival however inequalities in access to breast reconstruction services were identified.
b) Another audit of care received by head and neck cancer patients is ongoing.
c) We commenced a Lung Audit however due to staff change we postponed this to recommence in 2016 for 2014 data to enable comparisons with Lucada audit undertaken for the rest of the UK.

In addition to providing accurate, timely data on cancers in N. Ireland for Official Statistics by March 2017 for 2015 diagnosed patients the key priorities for 2016/17 agreed after our Planning & Development Day are to:

- Update Registry IT System – this will require additional resources.
- Achieve ISO27001 recognition for data security – this may require additional resources.
- Enhance datasets available to Registry e.g. recurrences, co-morbidities., translation tables to accommodate ICDO3.
- Undertake feedback to clinicians on CaPPS data fields to enhance quality of data items received.
- Work to achieve health economic resource for Registry.
- Seek to have Northern Ireland data available for comparing with UK wide cancer audits.
- Provide data for UKIACR Performance Indicators, and international comparator studies such as CONCORD, EUROCARE and Cancer Incidence in V Continents.
- Ensure continued access to COIS while acquiring RISOH downloads/access and access to radiology, as per Trust agreements.
- Develop a Standard Operating Procedure for identifiable data releases.
- Establish a costing framework for information requests.
- Develop a succession plan.
- Enhancing communication of Cancer Registry Data to researchers and public and ensure all relevant staff have media training.

As happens every year the Registry has opportunities to undertake additional work essential to enhance data available for service planning and monitoring research or education. If minor, these are usually undertaken within resources. The Registry for example is in a unique position to provide data required for monitoring of targets in the Northern Ireland Cancer Services Framework. This extensive piece of work would require additional resources.

While the N. Ireland Cancer Registry has had a successful year, we face some difficulties in the years ahead:

1. The number of cancer cases has risen by 37.4% per year since records began in 1993. This increase, driven by the ageing population is predicted to continue so that

by 2025 we predict that 14,000 cases of cancer (excluding NMSC[1]) will be diagnosed annually (a 65% projected increase from current levels).

The registry is expected to record more data items on each case, for example, stage and grade of cancer (receptor status for breast cancers), coexisting comorbidities, all treatments, recurrences, routes to diagnosis (e.g.) screening, A&E, red flag etc. in addition to the routine data on date and basis of diagnosis, morphology, demographic details etc.

2. The Registry has been hosted by Queens University Belfast (QUB) for 22 years, initially on a 5-year rolling contract with the Department of Health and since April 2010 with an annual payment from the Public Health Agency. QUB identifies this funding as an annual grant for a research project which fails to appreciate the ongoing nature of this arrangement. As a result many registry staff are on short term and/or temporary contracts with short term funding. This has resulted in difficulties in staff recruitment and staff retention. Despite these uncertainties we have a dedicated group of staff who are trained in this discipline to an advanced level. Cancer registration is a technically demanding task where knowledge regarding anatomy, the disease process and medical information in records and reports is required. Training is specific and requires several years to build up complete knowledge hence short term contracts do not suit the nature of the work. In order to maintain the high level of data accuracy and staging achieved this year, retention of these trained staff is key and having the Registry funded on a longer term basis is essential to achieve this.

3. There are severe constraints on the budget, currently 94% of the Registry budget is utilised on staff salaries and overheads*. (1.6% equipment, 1.8% pathology support/record retrieval from BSO with the remainder on training/travel/ postage/membership fees/ photocopying/printing/stationery/conference fees/books/consumables etc.)*. This leaves little room for manoeuvre of further development of the service provided by the Registry or even to ensure we maintain our existing timescales to produce accurate datasets within timescales.

4. We have enhanced the NICR with additional data and improved data quality and completeness with the same resources. We now have excellent datasets extending over 22 years on patients diagnosed in Northern Ireland with cancer and precancerous lesions. These datasets as well as our factsheets are encouraging

[1] NMSC = non melanoma skin cancer which accounts for 25% of new cancer cases diagnosed but causes few deaths.

clinicians to consider using the data held in the NICR. This is very welcome but adds considerably to the workload of the IT staff, statisticians, TVO's and the data manager. While we have introduced several efficiencies though training, improving business processes and acquisition of new data sources, increased constraints on our budget will now impact on our ability to perform existing services and our capacity to provide additional services.

We believe that the Registry has an exciting future providing essential and innovative datasets on cancer in N. Ireland for service planning and evaluation, research and education. However, with increasing numbers of cases and complexity of data request the current status of short term contracts is untenable.

Dr Anna Gavin
Director, N. Ireland Cancer Registry
June 2016

Ethics and patient confidentiality

The Registry has approval for its databases from the Office for Research Ethics Committees Northern Ireland (ORECNI) Reference 15/NI/0203. It is registered with the Data Protection Act - Registration Number (QUB): Z6833827. Each research project has separate ethical approvals.

The Registry has a leaflet and Poster available to inform patients, clinicians and the public about the work of the Registry. In 2014 a video was developed to inform a wider audience of the work of the Registry available at www.qub.ac.uk/nicr.

The method for removal of patients' data if requested is to notify the organisation providing data to the Registry of the relevant Health and Social Care Number so a block can be placed to prevent notification to the Registry.

Governance

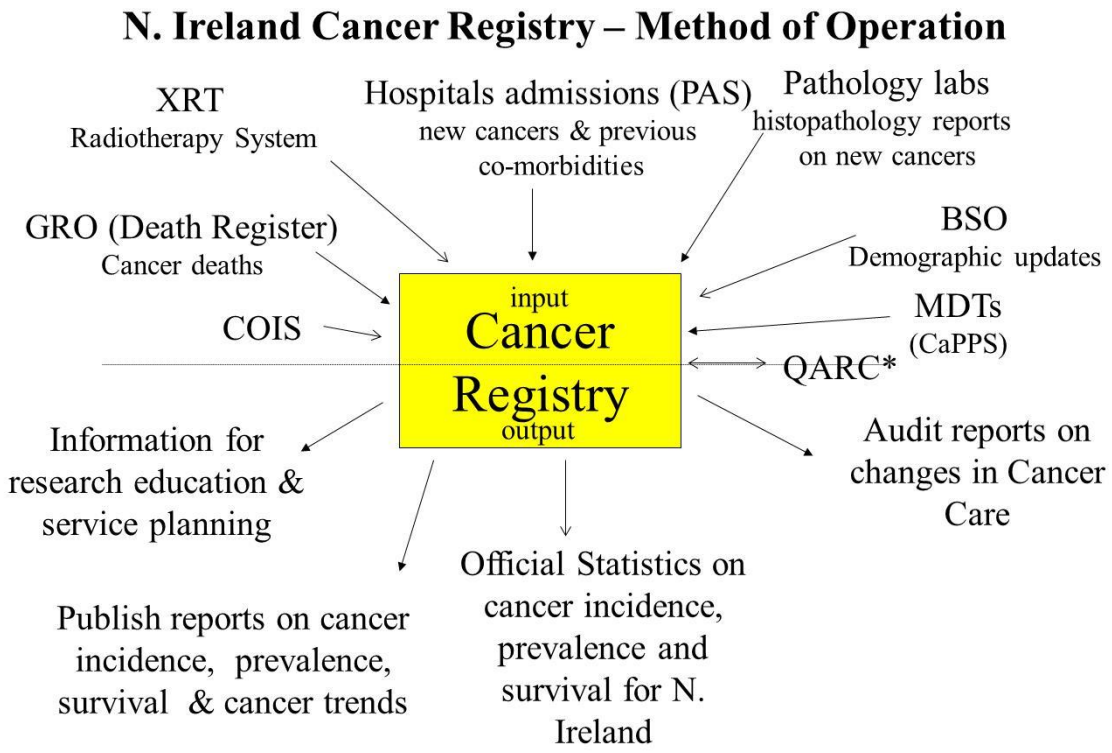
The registry finances are organised and monitored by Queens University financial processes.

The registry has a steering group which meets quarterly and a council which meets twice a year.

Agreements exist between all data sources and the Registry.

Method of Operation

The NICR acquires notifications of likely cancer diagnoses in the population electronically from pathology laboratories, hospital discharges (PAS) and death registrations (GRO). These are validated as true cancers by checking clinical records including the multidisciplinary team datasets provided by the Cancer Patient Pathway System (CaPPS), the Clinical Oncology Information System (COIS), Lab Centre Records and by note review. Datasets are then anonymised for analysis. Data received from Business Services Organisation (BSO), the Radiotherapy System, COIS and QARC (Quality Assurance Reference Centre) supplement the notifications by adding staging, radiotherapy/ chemotherapy treatments, updates to demographic information, such as GP, address and death data and screening data for breast, cervix and colorectal cancers. We also now received PAS downloads which include all hospital admissions since 1 January 2006 for cancer patients to determine patient co-morbidities.



*Registry provides data to quality assure Cancer Screening Services and to facilitate the work of the Clinical Genetics service (QARC = Quality Assurance Reference Centre).

The Registry links with patients by:

- Having patients represented on the Council of the Registry.

- Including patients in steering groups for specific projects.
- Involving cancer charities in the work of the Registry.
- Including patients in report launches etc.
- The Registry plans to develop a user group which will include patients.

Focus for 2016/17

The Registry will continue to work towards achieving the ten main goals identified in the Registry's 5-year Strategic Plan April 2013 – March 2018. The Registry which is funded by the Public Health Agency (PHA) will work to ensure the data needs of the PHA and Northern Ireland Cancer Network (NICaN) are prioritised. The priorities for 2016/17 are identified below and will also take account of the Queen's University Research Strategy, the priorities of which include international research partnerships, achieving excellence, supporting post graduate training to maximise academic, social and economic impacts.

In addition to providing accurate, timely data on cancers in N. Ireland for Official Statistics the key priorities for 2016/17 are to:

- Update Registry IT System – this will require additional resources.
- Achieve ISO27001 recognition for data security – this may require additional resources.
- Enhance datasets available to Registry e.g. recurrences, co-morbidities.
- Meet demands of increased numbers of registrations, 40% in past 20 years, 60% increase predicted from 2015-2025.
- Work to achieve health economic resource for Registry.
- Manage budget to meet new demands such as funding ICBP Phase 2.
- Seek to have Northern Ireland data available for comparing with UK wide cancer audits.

Goal 1 – Ensure high quality, timely, complete data on cancers and pre-malignant conditions occurring in the population of N. Ireland

Key Actions

a) Launch official statistics of cancer incidence, prevalence and survival statistics for 2015 Northern Ireland patients by March 2017.
b) Provide accurate Northern Ireland data for international comparison.
c) Improve staging data available on each patient to maintain goal of high overall staging (80% achieved for 2014 data).

d) Update Registry IT System.
e) Continue to enhance links with Business Service Organisation (BSO), Trusts, General Registrar's Office (GRO) and screening services to enhance data available on cancer registrations i.e. pathology, treatment and co-morbidity data.
f) Establish new links with RISOH System to ensure relevant datasets are available to NICR.
g) Ensure that the NICR has continued look up access to the COIS dataset.
h) Maintain links with development in cancer registration techniques.

Goal 2 – Protect the confidentiality of the data

Key Actions

a) Work towards achieving ISO27001 Certification in Information Security Management for NICR.
b) Ensure current practices and staff training is maintained.
c) Ensure research projects adhere to the NICR & QUB Research and Data Protection Protocols.

Goal 3 – Provide a cancer intelligence service

Key Actions

a) Answer all data requested within 20 days for general requests and 10 days for genetic requests. Continue to facilitate the Northern Ireland Clinical Genetics Service access to NICR datasets for clinical purposes.
b) Feedback research findings to relevant partners and associated patient groups.
c) Ensure website is kept up to date.
d) Work to provide N. Ireland data for national audits and peer review eg Lucada, Oesophago-gastric, Bowel Audit and CRUK Audit of delays in primary care.
e) Work to provide information for local cancer audits and outcomes of care as required by PHA, NICaN and Trusts.
f) Produce updated cancer factsheets from Official Statistics.
g) Ensure NICR website is aligned with new QUB web design.

Goal 4 – Facilitate the planning and monitoring of cancer services in Northern Ireland

Key Actions

a) Evaluate the quality of completion of the Cancer Patient Pathway System (CaPPS) databases at Trust level and feedback to Trusts.
b) Complete the lung regional audit in collaboration with clinicians and service managers within budget and timescales.
c) Ensure audit and research findings are disseminated to key organisations/ individuals to encourage implementation of recommendations.
d) Achieve resources to undertake additional audits of patterns of care for cancer patients to ensure continuation of regular data on process of care for patients.
e) Enhance availability of information on website and dissemination of data and reports through other online partners.

Goal 5 – Undertake and present internationally recognised research

Key Actions

a) Apply for 2 research grants.
b) Submit 8 papers for peer review in high impact journals.
c) Explore working with cancer data from all of UK/Internationally.
d) Continue to enhance the development and quality of the Prostate Specific Antigen database, up to 2015.
e) Complete Module 4&5 of the International Cancer Benchmarking Partnership**.**
f) Complete the ICBP Module 5 lung audit in collaboration with clinicians and service managers within budget and timescales.
g) Achieve funding for ICBP Phase 2 – research projects.
h) Ensure N. Ireland provide relevant data for ICBP Phase 2.
i) Work to enable UK PCUK Patient Reported Outcomes Measures (Life After Prostate Cancer) Study for Northern Ireland, Scotland and Wales starts 2016 (externally funded).
j) Establish Normative Study for baseline of population urological symptoms by mid 2016 (externally funded).
k) Submit abstracts and attend relevant conferences.

Goal 6 - Ensure the Registry provides value for money

Key Actions

a) Manage annual budget from Public Health Agency and provide accurate updates on spend with reference to the increased numbers of cases and increased data items being collected and need to provide funding for ICBP Phase 2 sign up.
b) Manage budgets from research grants.
c) Involve staff in planning of targets for 2016/2017.

Goal 7 – Ensure the sustainability of the Registry

Key Actions

a) Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.
b) To inform and support relevant stakeholders in the development of a legislative framework for secondary use of clinical data including cancer.
c) Ensure staff are trained to a high level for their work.
d) Maintain a high registry profile locally and internationally.
e) Achieve additional grant income.
f) Provide information as required for PHA review of Registry.
g) Organise opportunities to highlight the work of the Registry to external groups.

Goal 8 – Ensure good links with patients and their representatives

Key Actions

a) Continue to involve patients and their representative in planning in our Council and Steering group and in Registry work.
b) Involve patients as speakers/invitees at launch of reports and in Registry work.
c) Develop new Patient Information Leaflet to reflect detail of legislative framework for cancer registration now achieved.
d) Continue to enhance the NICR website to better disseminate and improve access to NICR data to improve public understanding of cancer in Northern Ireland.
e) Provide regular inputs to the Knowledge Exchange website/database.
f) Ensure data available to the public on cancer in N. Ireland is up to date and accurate.
g) Establish a N. Ireland Cancer Registry User Group to inform decisions on production and availability of statistics, data collected and support for research.

Goal 9 – Promote expertise of data acquisition and analysis

Key Actions

a) Use expertise of data acquisition and analysis for promotion of data availability for other diseases.
b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool.

Goal 10 – Provide an environment for education and training

Key Actions

a) Offer training slots to 2 undergraduate and 2 postgraduate students and 1 Public Health trainee.
b) Raise awareness of the Cancer Registry within the University and beyond.
c) Ensure training in survival analysis techniques to enhance Registry statistical expertise.
d) Input to organisation of 2016 National Cancer Intelligence Network conference.
e) Maintain international links on new development in cancer registration and cancer research.

Table 1: Registry Targets 2016/17

Targets	Action	Target Completion Date
Goal 1– Ensure high quality, timely, complete data on cancers and pre-malignant conditions occurring in the population of N. Ireland		
a) Launch official statistics of cancer incidence, prevalence and survival statistics for 2015 Northern Ireland patients by March 2017.	Data received and matched	September 2016
	Complete Resolving	December 2016
	Stats completed for web	March 2017
	Prepare Materials for minister etc.	March 2017
	Site specific reports to be written	March 2017
	Data on webpage	March 2017
b) Provide accurate Northern Ireland data for international comparison.	Concord	Late 2016
	Eurocare	June 2016
	Cancer in V Continents	June 2016
	UK Data repository	December 2016
	ICBP module 5 – analysis and results	December 2016
c) Improve staging data available on each patient to maintain goal of high overall staging (80% achieved for 2014 data).	Continue to work on Haematology datasets	Ongoing
	Continue with pathology support to enhance staging	Ongoing
	Achieve full pathology reports from private sector	April 2016
d) Update Registry IT System.	Undertake scoping exercise for existing systems by meetings/visits	September 2016
	Develop a business case for requirements	June 2016
	Seek funding for new IT System	December 2016
e) Continue to enhance links with Business Service Organisation (BSO), Trusts, General Registrar's Office (GRO) and screening services to enhance data available on cancer registrations i.e. pathology, treatment and co-morbidity data.	Invite Trust cancer managers to Registry and Council meeting	May 2016
	Meet with screening service re Agreements	September 2016
	Request regular updates to patient information and prescribing data from BSO	April 2016 / July 2016 / November 2016
	Request regular death updates from GRO	April 2016 / July 2016 /

Targets	Action	Target Completion Date
		November 2016
	Ensure agreements reflect any change in legislation	December 2016
f) Establish new links with RISOH System to ensure relevant datasets are available to NICR.	Attend relevant meetings and liaise with relevant RISOH manager	January 2016
g) Ensure that the NICR has continued look up access to the COIS dataset.	Liaise with COIS managers and relevant Belfast Trust staff	January 2016
h) Maintain links with development in cancer registration techniques.	Attend regular meetings: - UKIACR Executive (4 per year) - UKIACR Analysts Group (4 per year) - UKIACR Coding & Classification Group (4-5 times per year) - TNM Coding & Classification	
Goal 2– Protect the confidentiality of the data		
a) Work towards achieving ISO27001 Certification in Information Security Management for NICR.	• Identify scope of Information Security Management System and identify information assets. • Perform risk assessment identifying threats and vulnerabilities. Document controls and procedures to mitigate risks to assets. • Implement ISMS controls and policies by means of publishing documentation and staff awareness training. • Arrange for internal audit to assess ISMS. Make any adjustments/improvements. • Arrange for accredited certification body to assess ISO27001 for certification to the standard.	March 2016 May 2016 August 2016 November 2016 February 2017
b) Ensure current practices and staff training is maintained.	Implement existing policies	Ongoing

Targets	Action	Target Completion Date
c) Ensure research projects adhere to the NICR & QUB Research and Data Protection Protocols.	All registry outputs including information requests, general reports, presentations, audits and research papers to adhere to SOP on release of data	Ongoing
Goal 3 – provide a cancer intelligence service		
a) Answer all data requested within 20 days for general requests and 10 days for genetic requests. Continue to facilitate the Northern Ireland Clinical Genetics Service access to NICR datasets for clinical purposes.	Monitor requests as they come in with annual review of times taken	Genetic Requests – within 10 days of receipt
		General Requests – within 20 days of receipt
	Annual Review	March 2017
b) Feedback research findings to relevant partners and associated patient groups.	Research papers to have 'implications for service' sheet developed and shared with PHA	Ongoing – summary by March 2017
c) Ensure website is kept up to date.	Relevant items brought to Team meeting	6 monthly review
	Items to web page	6 monthly review
d) Work to provide N. Ireland data for national audits and peer review eg Lucada, Oesophago-gastric, Bowel Audit, CRUK Audit of delays in primary care.	Dependent on achieving legislative framework Prepare data for future submission for: - Lung - Head & Neck cancers	 December 2016 July 2016
e) Work to provide information for local cancer audits and outcomes of care as required by PHA, NICaN and Trusts.	Keep record of requests and resource required	Ongoing
	Review at end of year	March 2017
f) Produce updated cancer factsheets from Official Statistics.	Produce factsheet for major cancers and access via website	June 2016
g) Ensure NICR website is aligned with new QUB web design.	Redesign NICR website to align with new QUB web design	September 2016
Goal 4 – facilitate the planning and monitoring of cancer services in Northern Ireland		
a) Evaluate the quality of completion of the Cancer Patient Pathway System (CaPPS) databases at Trust level and feedback to Trusts.	Decide: - What variables to feedback - Period of feedback - Frequency of feedback	December 2016

Targets	Action	Target Completion Date
	- Who should receive feedback	
	Pilot first with lung	September 2016
	Establish for all MDTs	March 2017
b) Complete the lung regional audit in collaboration with clinicians and service managers within budget and timescales.	Data collection, analysis & Report Writing Lung cancers	December 2016
c) Ensure audit and research findings are disseminated to key organisations/ individuals to encourage implementation of recommendations.	Presentation of research findings to project steering group etc.	Before articles are submitted to peer review journal
	Draft peer review papers/reports etc to be submitted to PHA (researchers to submit to Office Manager for onward submission to PHA)	6 weeks prior to publication where possible
	Final 'Word' version of paper accepted by journal for publication (including any amendments requested by journal) to be forwarded to Office Manager for inclusion in Pure monitoring system	As soon as paper has been accepted by journal
d) Achieve resources to undertake additional audits of patterns of care for cancer patients to ensure continuation of regular data on process of care for patients.	Achieve additional resources to undertake audits eg Head & Neck, Lung along Lucada lines	March 2017
e) Enhance availability of information on website and dissemination of data and reports through other online partners.	Monthly review of information available	Ongoing
Goal 5 – undertake and present internationally recognised research		
a) Apply for 2 research grants.	Ensure awareness of available grants	Ongoing
	Apply for 2 grants	March 2017
b) Submit 8 papers for peer review in high impact journals.	Submit 8 papers.	March 2017

Targets	Action	Target Completion Date
c) Explore working with cancer data from all of UK/Internationally.	Build on links with National Cancer Intelligence Network and Farr Institute, attending relevant meetings.	March 2017
d) Continue to enhance the development and quality of the Prostate Specific Antigen database, up to 2015.	Identify resource required	August 2015April 2016
	Seek resource to undertake task.	September 2017
e) Complete Module 4&5 of the International Cancer Benchmarking Partnership.	Module 4 – Continue to recruit ovary patients	Ongoing – due to finish when international analysis commences – date yet to be decided likely mid 2016
	Undertake local analysis breast, bowel, lung and comment on international analysis	December 2016
f) Complete the ICBP Module 5 lung audit in collaboration with clinicians and service managers within budget and timescales.	Provide information for any queries	March 2016
	Comment on draft outputs	March 2017
g) Achieve funding for ICBP Phase 2 – Research Projects.	Achieve contract	March 2016
	Monitor budgets carefully	March 2016
h) Ensure N. Ireland provide relevant data for ICBP Phase 2.	Ensure attendance at Board and Subgroup meetings in collaboration with PHA	Ongoing 4 per year (Board meetings and various)
	Comment on research proposals	As required
	Seek additional funding if required	As required
	Keep DHSS and PHA informed	After relevant meetings
i) Work to enable UK PCUK Patient Reported Outcomes Measures) Life After Prostate Cancer) Study for Northern Ireland, Scotland and Wales starts 2016 (externally funded).	Achieve Ethics for N. Ireland, Scotland and Wales	March 2016
	Maintain contact with local urology leads	Ongoing
	Survey implementation	July 2016
	Analysis of results	September 2016
	Report available	October 2016
j) Establish Normative Study for baseline of	Achieve ethics	April 2016

Targets	Action	Target Completion Date
population urological symptoms by mid 2016 (externally funded).	Analysis of results	September 2016
	Survey Distribution etc.	June 2016
	Analysis of results and report	August 2016
k) Submit abstracts and attend relevant conferences.	Present at NCIN conference/IARC Conference	June 2016
	Abstracts submitted for ENCR Meeting/Conference	October 2016
	Abstracts submitted for International Association of Cancer Registries conference and attendance	October 2016
	Abstracts submitted for NCRI conference	November 2016
Goal 6 - Ensure the Registry provides value for money		
a) Manage annual budget from Public Health Agency and provide accurate updates on spend with reference to the increased numbers of cases and increased data items being collected and need to provide funding for ICBP Phase 2 sign up.	Monitor budget	Quarterly
b) Manage budgets from research grants.	Monitor budget	Quarterly
c) Involve staff in planning of targets for 2016/2017.	Host NICR Planning & Development Day	March 2016
	Invite Trust Cancer Managers and Steering Group	September 2016
	Staff to contribute to actions/completion dates	March 2016
Goal 7 – Ensure the sustainability of the Registry		
a) Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.	Raise with university/PHA where possible	Ongoing
b) To inform and support relevant stakeholders in the development of a legislative framework for secondary use of clinical data including cancer.	Continue communications with Chris Matthews and Department of Health	Monthly Contact
	Keep NICR Council/Steering Group informed	At each Group Meeting
	Maintain public awareness of Registry work	Ongoing
c) Ensure staff are trained to a high level for	Undertake training needs assessment for each person in	October 2016

Targets	Action	Target Completion Date
their work.	their annual appraisal	
	All relevant staff complete GCP training and make sure this is kept up to date every 3 years	September 2016
d) Maintain a high registry profile locally and internationally.	Engage with local/international conferences	March 2017
	Distribute/present NICR video	Ongoing
	Engage with media re Registry work	Ongoing
	Ensure relevant staff have media training	March 2017
	Continue on International Association of Cancer Registries Committee	2018
	Prepare and distribute high quality annual newsletter	July 2016
e) Achieve additional grant income.	Submit applications within deadlines	March 2017
f) Provide information as required for PHA review of Registry.	PHA to determine information needs	When required
g) Organise opportunities to highlight the work of the Registry to external groups.	Liaise with Trust Cancer Managers	Quarterly
	Attend NICaN Board and Clinical Groups	Quarterly
	Use website, newsletter and twitter appropriately	Ongoing
Goal 8 – Ensure good links with patients and their representatives		
a) Continue to involve patients and their representative in planning in our Council and Steering group and Registry work.	Ensure consumer representation on Steering Group for specific studies plus Council	Ongoing as required
	Re-invite representation from Patient Client Council	April 2016
b) Involve patients as speakers/invitees at launch of reports and in Registry work.	Request invitees and speakers via charities	At least one month in advance of any launch
c) Develop new Patient Information Leaflet to reflect detail of legislative framework for cancer registration now achieved.	Await detail of legislation likely 2-4 year timescale	Review 2018
d) Continue to enhance the NICR website to better disseminate and improve access to NICR data to improve public understanding	Increase the number of sites with summary statistics available to download	June 2016
	Include prevalence data in the factsheets	June 2016

Targets	Action	Target Completion Date
of cancer in Northern Ireland.		
e) Provide regular inputs to the Knowledge Exchange website/database.	Initiate contact	July 2016
f) Ensure data available to the public on cancer in N. Ireland is up to date and accurate.	Liaise with Macmillan re Cancer Toolkit.	April 2016
	Provide regular data to CRUK	May 2016
	Provide regular data to NINIS	May 2016
g) Establish a N. Ireland Cancer Registry User Group to inform decisions on production and availability of statistics, data collected and support for research.	Establish a NICR user Group with representatives from PHA, DHSSPS, patients, Trusts and researchers.	March 2017
Goal 9 – Promote expertise of data acquisition and analysis		
a) Use expertise of data acquisition and analysis for promotion of data availability for other diseases.	Provide advice to other Registries eg Cerebral Palsy, others as requested	March 2017
	Work with grant holders to ensure population based registry within ethical agreements for colorectal polyps, MGUS and Endometrial Hyperplasia	March 2017 & Ongoing
b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool.	Link with European Network of Cancer Registries to have articles in their newsletter and to attend relevant scientific meetings	March 2017
	Membership of International Association of Cancer Registries (IACR)	Ongoing
	Continue to support requests for Staging Tool Online	Ongoing
	Arrange honorary contract with key staff	July 2017
Goal 10 – Provide an environment for education and training		
a) Offer training slots to 2 undergraduate and 2 postgraduate students and 1 Public Health trainee.	Offer undergraduate summer studentships	April 2016 for Summer 2016
	Offer suitable projects for postgraduate students	March 2016
	Provide relevant projects for training	March 2017

Targets	Action	Target Completion Date
	Offer opportunities for international visitors from other cancer registries	March 2017
b) Raise awareness of the Cancer Registry within the University and beyond.	Collaborate with outside bodies	March 2017
	Attend conferences NCIN/UKIACR and other relevant conferences to present NICR work.	March 2017
	Annual newsletter	July 2016
c) Ensure training in survival analysis techniques to enhance Registry statistical expertise.	Applications to NCI Cancer Prevention Summer School for 2 staff	February 2016 – successful applications X2 for summer 2016
	2 new statisticians to attend LSHTM Survival course	June 2016
d) Input to organisation of 2016 National Cancer Intelligence Network conference.	Assist with programme development, abstract review and conference organisation	April 2016
e) Maintain international links on new developments in cancer registration and cancer research.	Attend relevant meetings - International Association of Cancer Registries - International Association Research Cancer - International Cancer Benchmarking Partnership meeting	 November 2016 June 2016 Ongoing

Financial Analysis

The Registry is primarily funded by the Public Health Agency (PHA) for the central business of running a population based cancer registry for N. Ireland, see central Registry tasks outlined in Table 2. The Registry also submits research and audit grant applications to various funding bodies and if successful undertake specific research/audit projects with this funding.

Table 2: Key Registry Tasks

Registry Key Tasks	Staff Involved	Comments
Provide Official Statistics for cancer incidence, survival and prevalence by defined dates annually	IT Staff TVOs Data Manager Analysts Director Clerical Staff	Statistics on cancer incidence and survival for 2015 will be published March 2017.
Maintain an up to date database of cancer registrations with high levels of case ascertainment and completeness of data items eg staging >76%, DCO rate <2%, 86% microscopically verified. Seek enhanced datasets et radiotherapy, prescribing to document co-morbidity	IT Staff TVOs Data Manager Medical Adviser Pathologists	
Ensure compliance with Data Protection by ensuring agreements for data exchange/release are accurate/up to date and in keeping with ethical and governance. This requires annual review, regular ethics application, linkage with Trust staff and regular staff training	Data Manager Clerical Staff Director Analyst Medical Advisor IT Manager	
Provision of data request services for up to 250 requests (56% genetic) to facilitate work of: - Clinical Genetic Service - Cancer service planners - Politicians - PHA/DHSS etc. - Cancer researchers	TVOs Data Analysts IT Staff Data Manager	

Registry Key Tasks	Staff Involved	Comments
Provision of Information on Cancer for the Public eg media queries and work, information on web page	Director Analysts Clerical Staff IT staff Medical Advisor Data Manager	
Enhance availability of information on webpage and dissemination of data and reports through other online partners	Analysts TVOs Director IT Staff Medical Adviser Data Manager Clerical Staff	
Provide population based data on pre-malignant disease eg - Colorectal polyp detection as part of screening program - Stage of disease presentation and survival after health campaigns - Provide data for Quality Assurance of Screening Services - Barrett's Oesophagus - Endometrial Hyperplasia - PSA Datbase	Analysts TVOs IT Staff Medical Adviser Data Manager	
Provision of Data for National Audits eg Lucada, International Benchmarking re - Cancer survival eg Concord/Eurocare/ ICBP - Cancer incidence eg cancer incidence in V continents, Globocan - EUROCIM - ACCIS (children)	TVOs IT Staff Data Analysts Director Medical Advisor Clerical Staff Data Manager	
Ensure all data requests for research meet the required ethical and registry standard operating procedures for release of data. Quality assure data in Registry and data requests	Director IT Staff Data Manager Analysts Clerical Staff	

Registry Key Tasks	Staff Involved	Comments
Work with Trusts to enhance recording of data on cancer patients by: - Working with Trusts on completeness of CaPPS - Feedback to Trusts - Input to Trust audits	Medical Adviser Analysts Director TVOs IT Staff Clerical Staff Data Manager	
Registry Admin - Personnel issues - Finance - Newsletter	Director Analysts Data Manager Clerical staff IT staff	
Research using Registry data - Ethics applications - Data analysis - Abstract & Paper writing - Conference attendance and presentation	Analysts Director Medical Advisor IT staff Data Manager TVOs	Conference travel grants available form QUB Note 10% Director salary covered by Proms research grant, previously covered by PHE
QUB related work - Teaching - Education facility for undergraduate and postgraduate students	QUB Professor Director Analysts IT Staff Clerical staff Data Manager	No overhead on Director and one other member of staff
Training	All NICR Staff	

Allocation from PHA

The allocation from the PHA is subject to a 12.5% overhead on salaries excluding Director, and one other member of staff (Table 3, Table 4).

Table 3: Allocation from PHA

Funding from Public Health Agency	Funding 2013/14	Funding 2014/15	Funding 2015/16	Funding 2016/17
Total	**£778,193**	**£801,778**	**£809,796**	**£820,112***

Table 4: Breakdown of allocation from PHA

Funding from Public Health Agency	Funding 2013/14	Funding 2014/15	Funding 2015/16	Funding 2016/17
Salaries	£640,537	£684,315	£682,201	£687,679+
Overheads	£64,276	£68,958	£67,792	£67,187+
Non-Pay	£73,380	£48,505	£59,803	£55,246+
Total	**£778,193**	**£801,778**	**£809,796**	**£810,112***

*£10,000 top-sliced by PHA for NICRs contribution to ICBP Phase 2
+Estimated breakdown

Other funding

In addition to the allocation from the PHA the Registry has several research/audit projects (See Table 5) these are used to fund staff additional to those funded by the PHA.

Table 5: Research/Audit Expenditure Relating to projects active during the period 1 April 2015 – 31 March 2016*

	Start Date	End Date	Total Budget	Expenditure up to 31/03/16	Balance C/F 2016/17
[1]**NAEDI**	01/06/12	31/03/16	£319,907	£319,907	£0
[2]**GAIN Breast**	01/08/14	31/03/16	£29,582	£29,582	£0
[3]**GAIN Lung**	01/02/15	31/03/17	£26,800	£11,658	£15,142
[4]**PCUK PROMS**	01/11/14	31/10/17	£540,982 (part of £1.2million grant with Leeds)	£116,897**	£424,085
[5]**Macmillan**	01/04/16	31/03/18	£118,587	£0	£118,587

*Budgets for April – March financial years for specific research projects are not available as starts dates vary and projects run over variable timeframes
**includes payment to Scotland. Wales will also receive payment for staff and services for this project from the budget held by NICR in QUB

1. Identifying targets for interventions to promote early diagnosis of cancer funded by Cancer Research UK - National Awareness and Early Diagnosis Initiative (NAEDI) (1 June 2012 – 31 March 2016).
2. Regional audit of investigation and current treatment of breast cancer patients diagnosed in N. Ireland funded by Guidelines Audit & Implementation Network (1 August 2014 – 31 March 2016).
3. Regional Audit of diagnosis and treatment of lung cancer patients in N. Ireland funded by Guidelines Audit & Implementation Network (1 February 2015 – 31 March 2017).
4. National Prostate Cancer Patient Reported Outcome Measures (PROMs) A comprehensive PROM programme to enhance understanding of outcomes that matter for men with prostate cancer and their families funded by Prostate Cancer UK (1 November 2014 – 31 October 2017) Note: funding held in Northern Ireland includes funding for the Scottish and Welsh proportion and the Normative study.
5. Improving Outcomes of Cancer Patients funded by Macmillan Cancer Support (1 April 2016 – 31 March 2018).

Appendix A: Update on Registry Targets 2015/16

Overview of 2015/16

The goals for the Registry were to continue to:

- Goal 1 – Ensure high quality, timely, complete data on cancers and pre-malignant diseases occurring in the population of N. Ireland.
- Goal 2 – Protect the confidentiality of the data.
- Goal 3 – Provide a cancer intelligence service.
- Goal 4 – Facilitate the planning and monitoring of cancer services in Northern Ireland.
- Goal 5 – Undertake internationally recognised research.
- Goal 6 - Ensure the Registry provides value for money.
- Goal 7 – Ensure the sustainability of the Registry.
- Goal 8 – Ensure good links with patients and their representatives.
- Goal 9 – Promote expertise of data acquisition and analysis.
- Goal 10 – Provide an environment for education and training.

Recently Completed Research/Audit Projects:

1. Improving patient survival in Northern Ireland – an investigation of factors affecting delays in cancer diagnosis as part of the International Cancer Benchmarking Partnership Module 4. Funded by Macmillan Cancer Support £56,204. Data collection completed except for ovary, Analysis to be undertaken on anonymised N. Ireland data at same time as other countries, expected late 2016.
2. Understanding how to improve the lives of men living with prostate cancer. Funded by Prostate Cancer UK. Completed by April 2015 - £109,148. Research papers are still being produced.
3. Report on mortality among Children and Young People (0-24 years) who survive cancers in N. Ireland – completed due for release late 2016.
4. Regional audit of investigation and current treatment of breast cancer patients diagnosed in N. Ireland (4 months of 2012). Funded by Guidelines & Audit Implementation Network £29,582. Report on 'Monitoring care for female breast cancer patients in Northern Ireland diagnosed 2012 (with comparisons to 1996, 2001 and 2006)' available February 2016.
5. Identifying potential targets for early diagnosis interventions in cancer. Funded by National Awareness and Early Diagnosis Initiative (NAEDI) through Cancer Research UK (CRUK) £319,907. Expected to be completed by early 2016 – Research papers are still being produced.

Ongoing/New Research/Audit Projects:

1. Regional Audit of diagnosis and treatment of lung cancer patients in N. Ireland (first quarter of 2013). Funded by Guidelines & Audit Implementation Network £26,800. To recommence June 2016 (See Appendix B).
2. National Prostate Cancer Patient Reported Outcome Measures (PROMs) A comprehensive PROM programme to enhance understanding of outcomes that matter for men with prostate cancer and their families. Funded by Prostate Cancer UK £540,982. To be complete October 2017 (NI award to also cover organisation of surveys in Scotland and Wales) (See Appendix C).
3. Improving Outcomes of Cancer Patients. Funded by Macmillan Cancer Support £118,587. April 2016 – March 2018 (See Appendix D). To include:
    a) Review of the profile of breast cancer patients managed through the Transforming Cancer Follow-up Pathway comparing them to all breast cancer patients (funded by Macmillan Cancer Support) (See Appendix D).
    b) Report on Breast Cancer recurrences and metastases (funded by Macmillan Cancer Support) (See Appendix D).
4. Provision of additional data on cancer patients to the NI Biobank (funded by NI Biobank) funding held by NI Biobank.
5. Do persons with severe mental illness have similar stage at diagnosis and screening histories and survival as cancer patients with mental illness.
6. Primary care audit of cancer patient pathway – National Cancer Diagnosis Audit with CRUK – discussions ongoing.
7. Investigations as proposed by ICBP Phase 2 including provision of N. Ireland data for update of International Cancer Survival comparing international cancer benchmarking partnership members for lung, colorectal and ovary cancers with inclusion of new cancers (pancreas, oesophagus, stomach and liver).

Collaborative projects using Registry data (undertaken by external researchers)

1. Molecular epidemiology projects with NI Biobank – Colon cancer
2. Molecular epidemiology projects with NI Biobank – Breast cancer

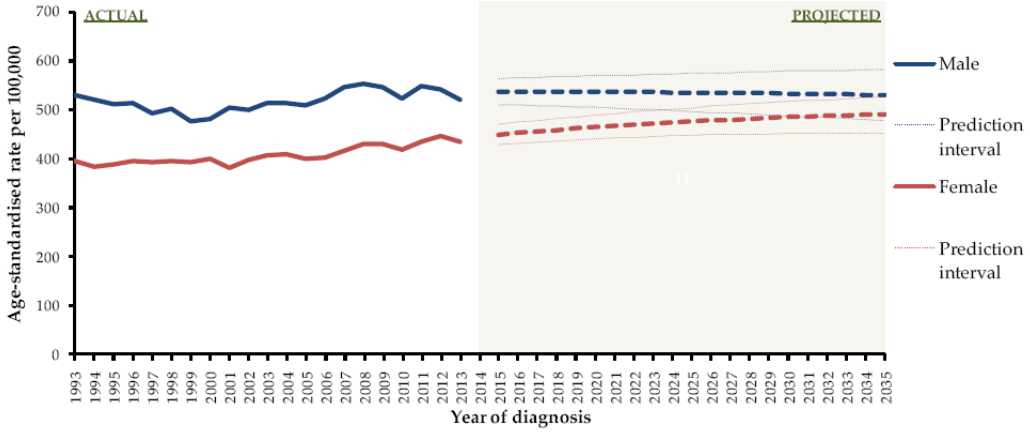
Projections

The Registry has compiled increasingly complete datasets on an increasing number of cancers diagnosed since 1993.

Age-standardised incidence rates of cancer (ex. NMSC) among men are projected to remain fairly steady in forthcoming years with no change by 2020 compared to rates in 2009-

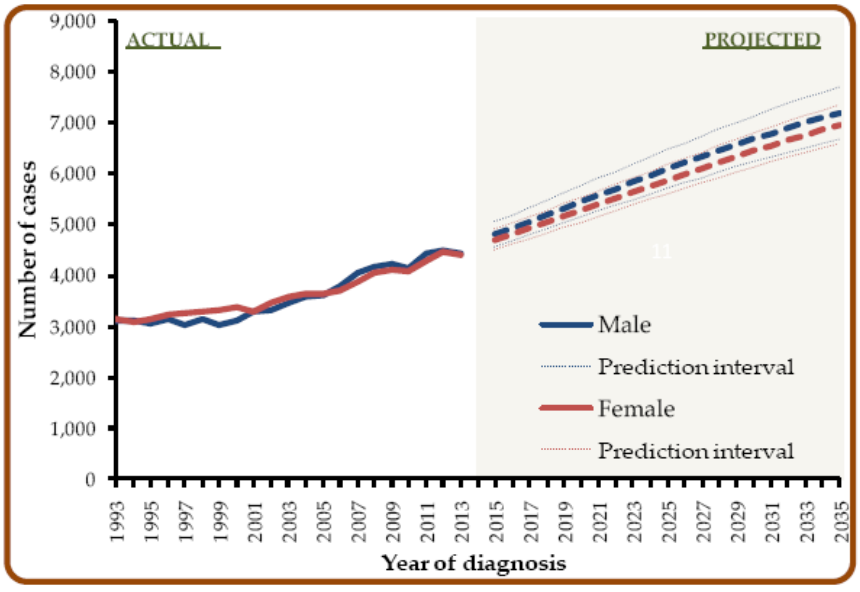
2013, while by 2035 a slight drop of 1% is expected. Among women however, incidence rates are expected to continue to increase with a 7% rise by 2020 and a 13% rise by 2035 (See Figure 1).

Figure 1: Cancer (ex. NMSC) incidence projections to 2035 by sex



In 2009-2013 there were 4,347 male and 4,275 female cases of cancer (ex. NMSC) diagnosed each year. By 2020 this is expected to rise by 25% for men and by 24% for women to 5,443 and 5,285 cases per year respectively. By 2035 the number of cases per year is projected to be 7,181 male and 6,967 female cases, a 65% rise among men and a 63% rise among women (See Figure 2).

Figure 2: Projected number of cases diagnosed from 2015 to 2035



By 2035 the most common cancers are expected to remain breast, colorectal, lung and prostate cancer, with the number of breast cancers expected to reach 2,000 cases per year and the number of male lung and colorectal cancers expected to exceed 1,000 cases per year (See Table 6).

Table 6: Projected number of cases diagnosed by sex and type in 2020 and 2035

Cancer type	Male					Female				
	2009-13 cases per year	2020		2035		2009-13 cases per year	2020		2035	
		Cases per year (prediction interval)		Cases per year (prediction interval)			Cases per year (prediction interval)		Cases per year (prediction interval)	
All (ex. NMSC)[1]	4,425	5,443	(5,140, 5,746)	7,181	(6,675, 7,687)	4,351	5,285	(5,050, 5,520)	6,967	(6,590, 7,344)
Bladder	150	169	(128, 210)	205	(162, 248)	61	67	(47, 87)	83	(62, 104)
Brain	81	94	(67, 121)	110	(76, 144)	55	63	(42, 84)	75	(49, 101)
Breast						1,268	1,589	(1,464, 1,714)	2,077	(1,888, 2,266)
Cervix						103	93	(56, 130)	74	(26, 122)
Colorectal	680	909	(807, 1,011)	1,292	(1,143, 1,441)	545	688	(605, 771)	946	(818, 1,074)
Kidney	173	244	(195, 293)	368	(294, 442)	115	161	(124, 198)	246	(189, 303)
Leukaemia	116	137	(101, 173)	170	(128, 212)	80	91	(66, 116)	116	(88, 144)
Liver	72	110	(77, 143)	179	(125, 233)	31	43	(24, 62)	67	(33, 101)
Lung	649	816	(717, 915)	1,128	(991, 1,265)	484	641	(570, 712)	923	(821, 1,025)
Melanoma	138	215	(168, 262)	370	(288, 452)	181	239	(193, 285)	317	(244, 390)
Myeloma	66	82	(54, 110)	104	(70, 138)	50	57	(38, 76)	74	(54, 94)
NHL	175	226	(182, 270)	316	(257, 375)	150	180	(146, 214)	232	(191, 273)
Oesophagus	127	163	(124, 202)	215	(165, 265)	65	72	(52, 92)	86	(63, 109)
Oral	140	204	(157, 251)	288	(204, 372)	73	103	(73, 133)	146	(96, 196)
Ovary[2]						158	178	(143, 213)	223	(183, 263)
Pancreas	105	135	(98, 172)	185	(139, 231)	116	156	(125, 187)	241	(198, 284)
Prostate	1,039	1,183	(1,040, 1,326)	1,294	(1,082, 1,506)					
Stomach	141	143	(107, 179)	140	(106, 174)	81	78	(56, 100)	76	(56, 96)
Uterus						238	343	(286, 400)	506	(411, 601)

NHL: Non-Hodgkin's lymphoma, NMSC: Non-melanoma skin cancer

[1] Excludes myelodysplastic syndromes and myeloproliferative disorders to maintain consistency in trends over time. Totals thus differ slightly from those on page I.

[2] Excludes borderline ovarian tumours to maintain consistency in trends over time.

The Registry also registers benign and uncertain cancers which are not included in the cancer incidence projections. These provide new information on cancer prevention initiatives. Figure 3 shows all registrations (malignant and other).

Figure 3: Registrations (Malignant and Other)

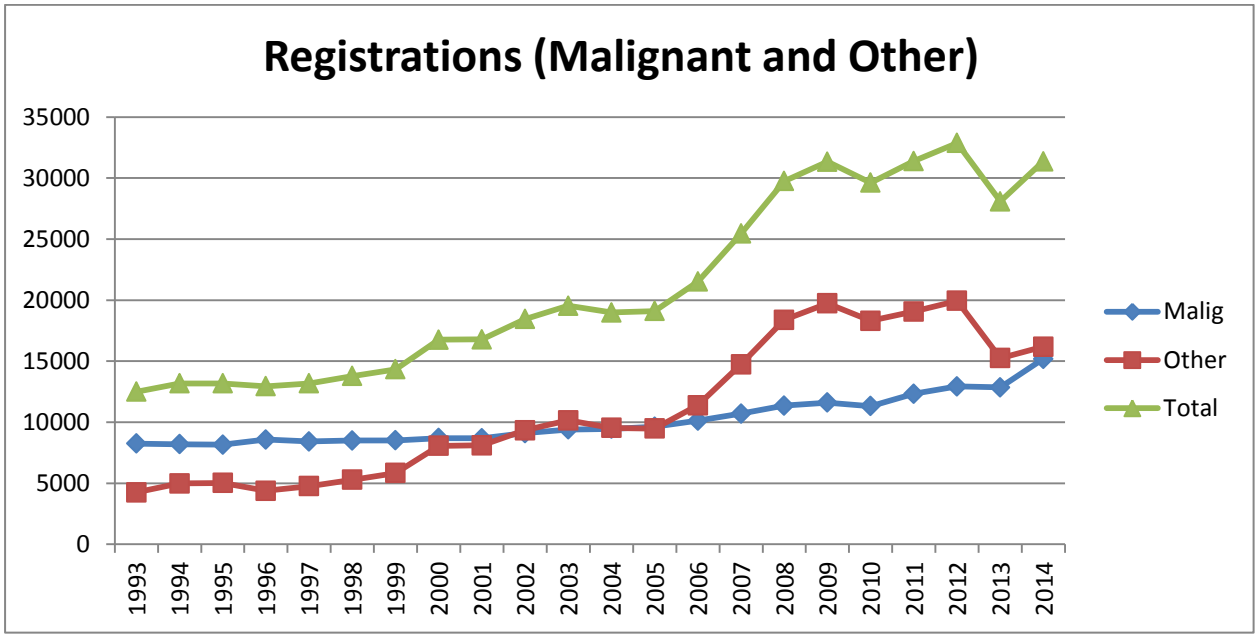


Table 7: Update on Registry Targets 2015/16

Goal	Targets	Progress Achieved
Goal 1– Ensure high quality, timely, complete data on cancers and pre-malignant disease occurring in the population of N. Ireland	a) Launch official statistics of cancer incidence, prevalence and survival statistics for 2014 Northern Ireland patients by March 2016.	– Official Statistics launched 22 March 2016. Available from www.qub.ac.uk/nicr.
	b) Improve staging data available on each patient to maintain goal of 76% overall staging.	– Achieved 80% for 2014 data. (See Appendix E).
	c) Continue to enhance links with Business Service Organisation (BSO), Trusts, General Registrar's Office (GRO) and screening services to enhance data available on cancer registrations i.e. pathology, treatment and co-morbidity data.	Agreements updated with data providers: – Belfast Trust (signed July 2015). – Western Trust (signed Aug 2015). – Southern Trust (signed Sept 2015). – South Eastern Trust (signed Sept 2015). – Northern Trust (signed Oct 2015). – QUB-BSO Agreement (Oct 2015). – QARC: Breast Screening (signed Sept 2015). – QARC: Cervical Screening (signed Oct 2015). – QARC: Colorectal Screening (signed Oct 2015). – NICR-NISRA (GRO) (Jul/Aug 2015). – NICR-NISRA (GRO) – Annex D (2015/16). – BSO-IT Data.

Goal	Targets	Progress Achieved
Goal 1cont'd – Ensure high quality, timely, complete data on cancers and occurring in the population of N. Ireland		New data source achieved: – Patient Administration System (PAS) episodes for cancer patients with previous co-morbidities – years 2006-2014. – Lab Centre for live access to blood results and pathology for cancer patients - this will enhance work with Biobank. – Pathology reports from Spire Private Pathology Lab who service the 352 Group. – Screening history for cervical cancer patients. – Screening history for colorectal cancer patients. All data sources included in Ethical Approvals.
	d) Aim to achieve access to relevant parts of electronic care patient record on cancer patients.	– Not achieved – would enhance data available to NICR on pre-diagnostic activity.
	e) Maximise use of electronic data sources.	– Pathology Text Reports. – Co-Morbidities via historic PAS. – PAS Cancer Diagnosis, all deaths. – Screening history for colorectal, breast and cervical cancers. } All received and matched electronically
	f) Ensure that links to COIS dataset are maintained.	– Work ongoing.
	g) Establish new links with RISOH System.	– Work ongoing –components due for implementation by the end of 2016.

Goal	Targets	Progress Achieved
Goal 2– Protect the confidentiality of the data	a) Ensure current practices and staff training is maintained.	– All new staff (n=4 TVOs, 1 Senior IM&T Officer, 3 statisticians/researchers) trained re data confidentiality.
	b) Ensure research projects adhere to the NICR & QUB Research and Data Protection Protocols.	– All projects vetted and compliance verified.
	c) Undertake preparatory work to achieve ISO27001 Certification in Information Security Systems.	– Staff member trained re ISO27001. – Subgroup established to determine steps to achievement. – Agreement of Registry Steering Group to proceed achieved at meeting held on 15 December 2015.
Goal 3 – provide a cancer intelligence service	a) Answer all data requested within 20 days for general requests and 10 days for genetic requests.	– 239 requests for information completed in 2015. – 99% of general requests completed within the recommended 20 working days. – 99% of genetic requests completed within the recommended 10 working days. – 269 Northern Ireland genetic requests completed by local Genetic Nurse. (See Appendix F).
	b) Feedback research findings to relevant partners and associated patient groups.	– Research papers (n=17) sent to PHA. – Breast audit report shared in draft form with clinicians December 2015. – Breast audit summary presented to NICR Council and Steering Group, 18 November 2015 and 15 December 2015 respectively.

Goal	Targets	Progress Achieved
Goal 3 cont'd – provide a cancer intelligence service	c) Ensure web page is kept up to date.	– Website updated Summer 2015 www.qub.ac.uk/nicr.
	d) Work to provide N. Ireland data for national audits and peer review eg Lucada, Oesophago-gastric and Bowel Audit.	– Northern Ireland data not eligible for inclusion in National Audits due to lack of legislative framework. – Lucada planned for 2016.
	e) Work to provide information for local cancer audits and outcomes of care as required by PHA, NICaN and Trusts.	– Information provided for PHA review of GI Consequences of Radiotherapy. – Colorectal trends in staging in the screening age group provided to PHA for the DPH report service. – Information provided to QARC for their submission to BASO.
Goal 4 – facilitate the planning and monitoring of cancer services in Northern Ireland	a) Evaluate the quality of completion of the Cancer Patient Pathway System (CaPPS) databases at Trust level and feedback to Trusts.	– Not completed due to staff changes.
	b) Complete the breast and lung regional audits in collaboration with clinicians and service managers within budget and timescales.	– Breast audit completed January 2016. – Lung audit postponed to 2016 with agreement of funders.
	c) Ensure audit and research findings are disseminated to key organisations/ individuals to encourage implementation of recommendations.	– Breast audit summary presented to NICR Council and Steering Group. – Draft of breast audit provide to relevant clinicians for comment.

Goal	Targets	Progress Achieved
Goal 4 cont'd – facilitate the planning and monitoring of cancer services in Northern Ireland	d) Achieve resources to undertake audit of 2012/13 diagnosed cancer patients for prostate cancer to ensure continuation of regular data on process of care for patients.	– Not achieved.
	e) Link with Trusts and NICaN group to determine Regional Cancer Audit Plan.	– NICR staff attended NICaN Board meetings and urology, breast and colorectal NICaN Group meetings.
	f) Enhance availability of information on webpage and dissemination of data and reports through other online partners.	– Website updated with positive feedback from users.
Goal 5 – undertake internationally recognised research	a) Apply for 2 research grants.	– Research grant provided by Macmillan Cancer Support.
	b) Submit 8 papers for peer review in high impact journals to include 4 additional papers from R&D/PCUK funded All Ireland prostate study.	– 17 papers published in peer review journals (See Appendix G).
	c) Explore working with cancer data from all of UK/Internationally.	– NICR engaged with phase 2 ICBP and currently working on completion of Phase 1. – Collaboration underway with University of Aberdeen and PHA on '2 week wait' referrals and cancer waiting times.

Goal	Targets	Progress Achieved
Goal 5 cont'd – undertake internationally recognised research	Cont'd	– Collaboration with university of Leeds, Oxford Brookes and University of Southampton on UK wide Life After Prostate Diagnosis
	d) Continue to enhance the development and quality of the Prostate Specific Antigen database, up to 2014.	– Initial investigation carried out by Ronan to determine if SQL Server functions could be useful for rebuild of this database. Further work required.
	e) Complete Module 4&5 of the International Cancer Benchmarking Partnership.	– Module 4 – Breast, colorectal and Lung data provided centrally, ovary still being collected. – Additional datasets re non-responders etc. being provided. – Module 5 – data on co-morbidity provided. – Module 5 – Information re NICR methods of data collection etc. provided.
	f) Complete the ICBP Module 5 lung audit in collaboration with clinicians and service managers within budget and timescales.	– Completed – awaiting central analysis.
	g) Achieve funding for Module 5 data of the International Cancer Benchmarking Partnership (£5,000+VAT).	– Achieved through Registry core budget.
	h) Achieve Northern Ireland sign up to second phase of ICBP.	– Achieved.

Goal	Targets	Progress Achieved
Goal 5 cont'd – undertake internationally recognised research	i) Establish UK PCUK Patient Report Outcomes Measures Study with Scotland and Wales commencing in Northern Ireland (externally funded).	– Regular meetings. – Questionnaire developed. – Ethical application submitted.
	j) Establish Normative Study for baseline of population urological symptoms (externally funded).	– Questionnaire developed and approved. – Ethical application due February 2016.
	k) Submit abstracts and attend relevant conferences.	– 15 abstracts submitted to Cancer Outcomes Conference. – 4 abstract submitted to International Association of Cancer Registries Conference. – See Appendix H) for conferences attended.
Goal 6 - Ensure the Registry provides value for money	a) Manage annual budget from Public Health Agency and provide accurate updates on spend.	– Budget managed - £809,796.
	b) Manage budgets from research grants.	– Budgets managed accurately.
	c) Involve staff in planning of targets for 2016/2017.	– Staff involved in Away Day and Business Plan preparation.
Goal 7 – Ensure the sustainability of the Registry	a) Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.	– This is an ongoing issue as many staff are on short term contracts for long periods while others are categorised as on permanent contracts with short term funding.

Goal	Targets	Progress Achieved
Goal 7 cont'd – Ensure the sustainability of the Registry	b) To inform and support relevant stakeholders in the development of a legislative framework for secondary use of clinical data including cancer.	– Director presented to Health Committee re draft – legislation currently making its way through system see http://www.niassembly.gov.uk/assembly-business/legislation/primary-legislation-current-bills/health-and-social-care-control-of-data-processing-bill/.
	c) Ensure staff are trained to a high level for their work.	– Training provided throughout the year (See Appendix H).
	d) Maintain a high registry profile locally and internationally.	– Registry included in several press releases. – Newsletter distributed to approx. 200 persons/institutions electronically. – 17 new disease specific Factsheets developed in conjunction with Official Statistics – available on website www.qub.ac.uk/nicr.
	e) Achieve additional grant income.	– Grant achieved from Macmillan Cancer Support – Improving outcomes of cancer patients - £118,587 over 2 years.
	f) Provide information as required for 2015/16 review of Registry.	– Review outline not yet decided. Awaiting information from PHA.

Goal	Targets	Progress Achieved
Goal 7 cont'd – Ensure the sustainability of the Registry	g) Organise opportunities to highlight the work of the Registry to external groups.	– Presented at GP Seminar: Diagnosing Upper GI & Pancreatic Cancer - September 2015. – Links established with Belfast Trust Head and Neck Clinicians which have led to 3 research opportunities. – Currently investigating linkage with Knowledge Exchange website.
Goal 8 – Ensure good links with patients and their representatives	a) Continue to involve patients and their representative in planning in our Council and Steering group and Registry work.	– Patients included in NICR Council and Cancer Focus representing patients on Steering Group.
	b) Involve patients as speakers/invitees at launch of reports and in Registry work.	– Patients involved in planning, committee, abstract judging, poster judging, chairing sessions etc. for Cancer Outcomes Conference.
	c) Replenish stocks of posters and Patient Information Leaflet in Trusts/GP Surgeries etc.	– Completed September 2015.
	d) Begin to enhance the NICR website to better disseminate and improve access to NICR data to improve public understanding of cancer in NI.	– NICR website updated with good feedback from users.

Goal	Targets	Progress Achieved
Goal 9 – Promote expertise of data acquisition and analysis	a) Use expertise of data acquisition and analysis for promotion of data availability for other diseases.	– Not achieved.
	b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool.	– Achieved via conferences. – Cancer Staging Tool now in use in 51 countries (See Appendix I).
	c) Ensure high quality input to the IARC Summer School if requested.	– Not requested.
	d) Increase online presence/visibility/impact of the Registry.	– Website updated.
Goal 10 – Provide an environment for education and training	a) Offer training slots to 4 undergraduate and 1 postgraduate student and Public Health trainees.	– 4 undergraduate students, 2 postgraduate students and 2 Public Health trainees. MSC student bioinformatics
	b) Raise awareness of the Cancer Registry within the University and beyond.	– Trainees in PHA provided with session on Cancer Registry 22/12/15. – Masters students provided with lecture on Disease Registries.
	c) Ensure training in survival techniques to enhance Registry statistical expertise if required.	– In house training provided to new statisticians. – 2 new statisticians to attend training in London School of Hygiene and Tropical Medicines, June 2016.

Goal	Targets	Progress Achieved
Goal 10 cont'd – Provide an environment for education and training	d) Organise Cancer Outcomes Conference 2015.	– Conference organised with 600+ delegates, 12 parallel session and 5 plenary sessions, very positive feedback received – came in on budget.
	e) Input to organisation of 2016 conference.	– 2016 Cancer Outcomes Conference still in early planning stage.

Appendix B - Regional Audit of diagnosis and treatment of lung cancer patients in N. Ireland

Lung cancer (including trachea, bronchus and lung) is the second most commonly diagnosed cancer in males, third in females (excluding non-melanoma skin cancer). It is the most common cause of cancer death in males and females. There were 1,134 cases diagnosed 2009-2013.

Evidence from Eurocare studies and more recently the International Cancer Benchmarking Partnership show survival for lung cancer, while improving still remains behind that of several comparable European and International Countries.

The N. Ireland Cancer Registry has documented changes to the process and outcome of lung cancer patients diagnosed 1996, 2001 and 2006, compared the services provided with guidelines and made recommendations for service changes. Two reports have been produced 'Lung Cancer Services Audit 1996 & 2001' (36 pages) and 'Monitoring care of lung cancer patients in Northern Ireland diagnosed 2006 with comparisons to 1996 & 2001' (70 pages) both available to download from http://www.qub.ac.uk/research-centres/nicr/Publications/AuditReports/

There has been much service changes since 2006 with the introduction of the electronic Cancer Patient Pathway System (CaPPS) to facilitate the management of MDTs, the introduction of Cancer Waiting Times targets, further consolidation of multidisciplinary team working and introduction of new diagnostic and treatment regimens with local guidelines aligned with NICR 2011 Guidelines recently signed off by the NICaN lung cancer group.

This audit will collect information throughout the patient journey including data on the tumour, disease stage at diagnosis, symptoms and symptom duration, pre-existing illnesses, routes of presentation, diagnosis and treatment timelines, investigations, treatments and outcomes. This data will provide insights into adherence to agreed guidelines and service changes since 2006 and make recommendations for further service improvement. We will use the previously collected LUCADA audit datasets to reduce duplication and enhance numbers audited.

This application is supported by the NICaN Lung Group lead Dr McAleese which will ensure audit recommendations will lead to service change.

Appendix C - National Prostate Cancer Patient Reported Outcome Measures (PROMs) A comprehensive PROM programme to enhance understanding of outcomes that matter for men with prostate cancer and their families

Aim

Prostate cancer (PCa) treatment may impact physically, psychologically and socially, affecting the quality of life (Qol) of men and their partners/spouses. Therefore in addition to improving treatments it is also important to measure the outcomes of treatments on patients and their partners/spouses so that services can be tailored to meet men's needs. This project aims to comprehensively assess men's QoL following diagnosis and treatment of PCa in order to gain detailed understanding of outcomes which matters to men and their partners/spouse, identify gaps in care and barriers to care improvements how to use PROMs to inform direct clinical care.

Funders: Prostate Cancer UK and Movember Foundation

Methodology

This project aims to collect data via questionnaire on over 75,000men with PCa (65,000 from England, 5433 from Scotland, 4,513 from Wales and 1,804 from Northern Ireland). The men will be identified through UK Cancer registration systems. Cross sectional and longitudinal surveys will be carried out to identify changes in outcome across time and the trajectory of morbidity burden. Qualitative research will also be carried out to reveal men's experience of living with PCa and how men and partners/spouses adapt to changing wellbeing and unmet needs over time.

In Northern Ireland, 4000 men of similar age from the general population will also be issued with a similar questionnaire to those men taking part in the study. This is to assess how common the problems reported by men with PCa are in the general population.

Time Scale

November 2014-October 2017

Current Status

In England 111 Trusts agreed to participate in the survey which represents over 85% of the total number of Trusts in England. Mail out of the surveys in England commenced in October 2015 and was completed in March 2016. To date, over 30,000 completed surveys have been returned, giving a return rate of over 60%. Qualitative interviews have also been completed with a sub section of this population. This first cohort of men will be re-surveyed in October 2016.

Ethical approval has been granted for the study to commence in Northern Ireland. All five trusts in Northern Ireland have agreed to participate. It is expected that the survey in NI will begin to be mailed out in May 2016, to approximately 2000 men diagnosed with prostate cancer between 1 of November 2012 to 30 November 2014. In Wales there are seven Health Boards and in Scotland there are fourteen. The Welsh and Scottish project teams hope to have all approvals in place in the next few weeks for mail out to commence at the end of May and beginning of June respectively. The devolved nations hope to emulate the success of England and achieve a high response rate. Ethical approval is currently being sought for the normative study in Northern Ireland.

Appendix D- Improving Outcomes of Cancer Patients

Aim

The NICR-Macmillan project aims to deliver insightful analysis of NI cancer data to support the improved design, testing and implementation of better models of care and to identify gaps and opportunities to deliver world class data collection and analysis for improved outcomes for people living with and beyond cancer.

Phase 1 – Year 1 (April 2016 –March 2017) work plan

1. *Primary Care Federation's Cancer Profiles*

NICR will report aggregated routine registration data, including incidence, mortality, prevalence and survival by the new Primary Care Federations with detail where appropriate on stage at diagnosis, age and deprivation. Part of the exercise will include investigation of using additional data sources available to NICR, such as CaPPS and hospital activity data, to further supplement the information. This will initially be piloted with prostate cancer in the West Belfast cancer federation. Estimated delivery date: July 2016

2. *Breast cancer recurrences and metastases*

Information on breast cancer recurrences will be reported on, using data collected from hospital notes and other sources. The collected information will also be compared to hospital activity information with the aim of identifying a method of routinely collecting and reporting recurrence data electronically. The work should align with in particular the Macmillan-NCIN development of a proxy to identify recurrence, second cancer and metastatic disease with potential of testing Macmillan-NCIN and, in the future, the Leeds recurrence algorithms. Estimated delivery date: March 2017

3. *Transforming Cancer Follow Up Profiles*

Macmillan will facilitate that NICR receive the Health and Social Care numbers of those patients on Transforming Cancer Follow Up. NICR will then provide aggregate information on routine registration data for these patients (including age, stage and deprivation) with comparisons to characteristics of total number of patients diagnosed with breast cancer during the same time period. This will initially be piloted with breast and prostate cancer patients diagnosed in 2013 with data on colorectal cancers produced at a later stage. Estimated delivery date: June 2016

4. Consequences of cancer and its treatment

NICR will draw on hospital activity data and – if and when possible – primary care data to explore and test the prevalence and severity of known consequences of cancer and its treatment. Areas to be investigated still to be confirmed by Macmillan-NICR project steering group. Some possible areas for investigation are:

a) Investigation of the consequences of pelvic radiotherapy (RT)
   Estimated delivery date: Feb 2017
b) Premature death among adults who have had cancer as children.
   Estimated delivery date: April 2016
c) Cardiotoxicity in breast cancer survivors.
   Estimated delivery date: Oct 2016

Phase 2 - *Potential* objectives for Year 2

Objectives for Year 2 of the Grant will be subject to discussion and mutual agreement at a steering group meeting in or around January 2017.

Current Status

- First meeting of NICR-Macmillan project steering group was held on Wednesday 20 April 2016.
- NICR have completed first draft of report on Childhood cancer.
- Analysis has begun on Primary care Federation's cancer profiles and Transforming Cancer follow up profiles.
- NICR have been attending calls of Macmillan-NCIN progressive cancers group which is working to establish a proxy to identify recurrence, second cancer and metastatic disease as work on Breast recurrences and metastases in NI will align with this.

Appendix E – Performance Indicators for 2014 Data

	UKIACR average	Northern Ireland
Registrations and Timeliness		
Year		**Northern Ireland**
2011		8,769
2012		9,029
2013		9,080
2013 (from Previous PI)		8,904
No. of 2014 not-finalised cases		N/A
No. of 2014 full cases		8,936
Registry creep		1.94%
Not-finalised cases		0.00%
Ascertainment		
Table No. & Parameters	**UKIACR average**	**Northern Ireland**
No. of Cases (current year) and percentage change vs. previous year (persons)		
All invasive xnmsc	75,452	8,936 (-0.3%)
All xnmsc 0-24	852	122 (14.4%)
All xnmsc 25-59	17,937	2,335 (0.2%)
All xnmsc 60-79	40,139	4,833 (0.9%)
All xnmsc 80+	16,533	1,689 (-4.8%)
Haematology	6,585	734 (-1.7%)
Head and Neck	2,418	311 (-4.1%)

	UKIACR average	Northern Ireland
Lower GI	9,331	1,229 (-7%)
Upper GI	3,318	449 (6%)
HPB	3,652	423 (-3.5%)
Trachea, Bronchus & Lung	9,709	1,214 (2.6%)
Melanoma	3,299	351 (2.5%)
Breast	11,674	1,301 (-1%)
Cervix	696	81 (-21.4%)
Other Female Genitals	3,877	483 (-0.8%)
Prostate	9,970	1,119 (6.1%)
Kidney	2,526	312 (3.9%)
Bladder	2,112	198 (-5.4%)
Brain and CNS	1,137	149 (13.5%)
Thyroid & other endocrine glands	805	85 (-3.8%)
CUP	1,869	201 (-2%)
Other invasive cancer	2,474	296 (3.1%)
Breast in situ	1,669	164 (6.3%)
Cervix in situ	6,773	1,148 (-2.4%)
Other tumours	10,388	3,116 (6.2%)
Non-Melanoma Skin Cancer	28,961	3,642 (0.7%)
Percentage (%) of death certificate only cases (persons) for 2014		
All invasive xnmsc	1.01%	0.68%
All xnmsc 0-24	0.19%	0.00%
All xnmsc 25-59	0.20%	0.17%
All xnmsc 60-79	0.57%	0.31%
All xnmsc 80+	3.38%	2.49%
Haematology	1.11%	0.54%
Head and Neck	0.61%	0.32%

	UKIACR average	Northern Ireland
Lower GI	0.68%	0.41%
Upper GI	1.25%	1.11%
HPB	1.94%	0.71%
Trachea, Bronchus & Lung	1.60%	0.66%
Melanoma	0.12%	0.00%
Breast	0.36%	0.31%
Cervix	0.44%	1.23%
Other Female Genitals	0.76%	0.21%
Prostate	0.57%	0.18%
Kidney	1.08%	0.64%
Bladder	1.00%	1.52%
Brain and CNS	0.90%	0.00%
Thyroid & other endocrine glands	0.76%	0.00%
CUP	4.89%	4.48%
Other invasive cancer	2.38%	4.39%
Breast in situ	0.00%	0.00%
Cervix in situ	0.00%	0.00%
Other tumours	0.49%	0.00%
Non-Melanoma Skin Cancer	0.03%	0.03%
Percentage (%) of zero survival cases (persons)		
All invasive xnmsc	1.51%	0.90%
All xnmsc 0-24	0.27%	0.00%
All xnmsc 25-59	0.36%	0.30%
All xnmsc 60-79	0.93%	0.46%
All xnmsc 80+	4.75%	3.02%
Haematology	1.68%	0.95%
Head and Neck	0.86%	0.32%

	UKIACR average	Northern Ireland
Lower GI	1.12%	0.65%
Upper GI	1.91%	1.56%
HPB	3.25%	0.71%
Trachea, Bronchus & Lung	2.38%	1.07%
Melanoma	0.12%	0.00%
Breast	0.41%	0.31%
Cervix	0.52%	1.23%
Other Female Genitals	1.14%	0.21%
Prostate	0.80%	0.27%
Kidney	1.84%	0.96%
Bladder	1.37%	1.52%
Brain and CNS	1.31%	0.00%
Thyroid & other endocrine glands	1.11%	0.00%
CUP	7.03%	5.47%
Other invasive cancer	3.40%	5.07%
Breast in situ	0.00%	0.00%
Cervix in situ	0.00%	0.00%
Other tumours	0.68%	0.00%
Non-Melanoma Skin Cancer	0.03%	0.05%
Percentage (%) of microscopically verified cases (persons)		
All invasive xnmsc	85.70%	87.21%
All xnmsc 0-24	90.28%	94.26%
All xnmsc 25-59	95.48%	95.55%
All xnmsc 60-79	88.82%	89.70%
All xnmsc 80+	64.92%	65.84%
Haematology	83.97%	89.78%
Head and Neck	96.86%	97.75%

	UKIACR average	Northern Ireland
Lower GI	90.36%	91.21%
Upper GI	92.39%	93.76%
HPB	56.30%	62.65%
Trachea, Bronchus & Lung	72.73%	71.83%
Melanoma	99.22%	99.43%
Breast	98.64%	99.46%
Cervix	97.90%	98.77%
Other Female Genitals	93.68%	96.69%
Prostate	88.58%	88.74%
Kidney	75.88%	82.37%
Bladder	88.73%	88.89%
Brain and CNS	71.18%	71.81%
Thyroid & other endocrine glands	94.13%	94.12%
CUP	45.97%	42.29%
Other invasive cancer	86.01%	88.85%
Breast in situ	99.04%	98.78%
Cervix in situ	99.91%	100.00%
Other tumours	82.23%	75.71%
Non-Melanoma Skin Cancer	98.38%	99.56%
Percentage (%) of non-specificity of morphology codes for cases which are microscopically verified		
All invasive xnmsc	3.19%	2.08%
All xnmsc 0-24	6.76%	0.00%
All xnmsc 25-59	2.59%	1.26%
All xnmsc 60-79	2.92%	1.78%
All xnmsc 80+	5.10%	5.13%
Haematology	21.43%	1.06%

	UKIACR average	Northern Ireland
Head and Neck	1.75%	2.96%
Lower GI	1.30%	0.98%
Upper GI	1.97%	1.19%
HPB	5.73%	0.38%
Trachea, Bronchus & Lung	3.11%	2.98%
Melanoma	0.02%	0.00%
Breast	1.72%	3.86%
Cervix	1.53%	1.25%
Other Female Genitals	1.60%	0.21%
Prostate	0.60%	0.91%
Kidney	1.39%	0.39%
Bladder	1.23%	1.14%
Brain and CNS	0.27%	0.00%
Thyroid & other endocrine glands	2.57%	1.25%
CUP	22.42%	25.88%
Other invasive cancer	2.09%	1.52%
Breast in situ	0.56%	0.62%
Cervix in situ	0.17%	0.00%
Other tumours	11.45%	38.15%
Non-Melanoma Skin Cancer	0.29%	0.83%
Mortality : Incidence ratios		
All invasive xnmsc	0.47	0.48
All xnmsc 0-24	0.13	0.14
All xnmsc 25-59	0.26	0.27
All xnmsc 60-79	0.45	0.46
All xnmsc 80+	0.78	0.82
Haematology	0.42	0.47

	UKIACR average	Northern Ireland
Head and Neck	0.33	0.41
Lower GI	0.38	0.36
Upper GI	0.81	0.78
HPB	0.85	0.88
Trachea, Bronchus & Lung	0.79	0.79
Melanoma	0.16	0.15
Breast	0.22	0.25
Cervix	0.28	0.30
Other Female Genitals	0.40	0.42
Prostate	0.24	0.21
Kidney	0.39	0.31
Bladder	0.54	0.60
Brain and CNS	0.78	0.74
Thyroid & other endocrine glands	0.16	0.24
CUP	1.10	1.14
Other invasive cancer	0.77	0.80
Breast in situ	0.00	0.00
Cervix in situ	0.00	0.00
Other tumours	0.06	0.03
Non-Melanoma Skin Cancer	0.01	0.01
Completeness of the dataset (%) - demographics and diagnostic details		
Patient's name	100.00%	100.00%
Patient's address	99.60%	100.00%
Sex	100.00%	100.00%
Ethnicity	45.52%	0.00%
Date of death (where dead)	99.93%	100.00%
Postcode	100.00%	100.00%

	UKIACR average	Northern Ireland
Date of birth	100.00%	100.00%
Unique health identifier	99.93%	99.94%
Anniversary (diagnosis) date	99.99%	100.00%
Site of primary growth	97.33%	97.63%
Type of growth	88.83%	88.90%
Behaviour of growth	99.91%	100.00%
Basis of diagnosis	97.90%	98.85%
Diagnosis with hospital	95.75%	96.74%
% of all cancer cases (xnmsc)		
Treatment	70.32%	70.13%
No Treatment	20.95%	N/A
Stage I and II patients receiving any treatment (%)	81.84%	78.38%
% of Cases treated with Surgery		
All invasive xnmsc	42.88%	46.69%
All xnmsc 0-24	50.02%	58.20%
All xnmsc 25-59	58.36%	57.99%
All xnmsc 60-79	41.64%	45.54%
All xnmsc 80+	27.05%	32.33%
Haematology	10.29%	9.54%
Head and Neck	45.19%	44.69%
Lower GI	63.01%	71.20%
Upper GI	24.56%	42.32%
HPB	35.13%	45.15%
Trachea, Bronchus & Lung	17.44%	24.63%
Melanoma	79.21%	56.98%
Breast	72.79%	76.71%
Cervix	50.25%	56.79%

	UKIACR average	Northern Ireland
Other Female Genitals	67.90%	64.39%
Prostate	16.57%	11.35%
Kidney	56.08%	70.51%
Bladder	72.52%	75.76%
Brain and CNS	50.31%	58.39%
Thyroid & other endocrine glands	75.33%	82.35%
CUP	11.07%	20.90%
Other invasive cancer	48.75%	53.04%
Breast in situ	80.80%	75.00%
Cervix in situ	64.71%	10.02%
Other tumours	53.88%	48.33%
Non-Melanoma Skin Cancer	66.86%	44.15%
% of Cases treated with Radiotherapy		
All invasive xnmsc	18.82%	26.15%
All xnmsc 0-24	11.99%	13.93%
All xnmsc 25-59	22.06%	31.69%
All xnmsc 60-79	20.45%	28.24%
All xnmsc 80+	10.53%	12.73%
Haematology	8.25%	11.04%
Head and Neck	49.80%	64.95%
Lower GI	11.68%	13.02%
Upper GI	14.72%	7.35%
HPB	2.25%	0.95%
Trachea, Bronchus & Lung	27.62%	37.15%
Melanoma	1.25%	0.85%
Breast	33.34%	52.42%
Cervix	40.22%	40.74%

	UKIACR average	Northern Ireland
Other Female Genitals	15.46%	19.25%
Prostate	15.27%	30.21%
Kidney	6.74%	10.58%
Bladder	12.68%	17.17%
Brain and CNS	44.31%	53.69%
Thyroid & other endocrine glands	28.27%	47.06%
CUP	9.88%	13.43%
Other invasive cancer	11.81%	14.53%
Breast in situ	31.37%	43.29%
Cervix in situ	0.07%	0.26%
Other tumours	1.37%	4.17%
Non-Melanoma Skin Cancer	1.29%	1.65%
% of Cases treated with Teletherapy		
All invasive xnmsc	19.88%	25.56%
All xnmsc 0-24	10.17%	10.66%
All xnmsc 25-59	22.32%	30.49%
All xnmsc 60-79	21.80%	27.87%
All xnmsc 80+	11.41%	12.55%
Haematology	9.39%	11.04%
Head and Neck	53.25%	64.95%
Lower GI	12.11%	13.02%
Upper GI	15.05%	7.13%
HPB	2.51%	0.95%
Trachea, Bronchus & Lung	28.62%	36.74%
Melanoma	1.40%	0.85%
Breast	38.15%	52.34%
Prostate	18.85%	30.03%

	UKIACR average	Northern Ireland
Cervix	35.43%	40.74%
Other Female Genitals	11.68%	17.60%
Kidney	7.87%	10.58%
Bladder	13.53%	17.17%
Brain and CNS	46.59%	53.69%
Thyroid & other endocrine glands	7.41%	9.41%
CUP	10.33%	12.44%
Other invasive cancer	12.07%	13.85%
Breast in situ	35.72%	43.29%
Cervix in situ	0.08%	0.17%
Other tumours	1.76%	3.98%
Non-Melanoma Skin Cancer	1.26%	1.62%
% of Cases treated with Chemotherapy		
All invasive xnmsc	21.42%	22.21%
All xnmsc 0-24	43.83%	44.26%
All xnmsc 25-59	33.84%	36.40%
All xnmsc 60-79	21.36%	20.96%
All xnmsc 80+	5.31%	4.03%
Haematology	37.25%	13.08%
Head and Neck	21.41%	15.11%
Lower GI	25.85%	25.79%
Upper GI	34.72%	44.54%
HPB	21.16%	26.95%
Trachea, Bronchus & Lung	23.80%	22.32%
Melanoma	1.31%	2.28%
Breast	28.96%	36.43%
Cervix	30.22%	32.10%

	UKIACR average	Northern Ireland
Other Female Genitals	27.28%	35.82%
Prostate	1.25%	3.04%
Kidney	6.64%	7.69%
Bladder	21.79%	23.23%
Brain and CNS	22.96%	29.53%
Thyroid & other endocrine glands	3.77%	4.71%
CUP	8.38%	8.96%
Other invasive cancer	23.49%	30.07%
Breast in situ	2.74%	8.54%
Cervix in situ	0.05%	0.26%
Other tumours	7.36%	9.92%
Non-Melanoma Skin Cancer	0.30%	0.88%
% of Cases treated with Hormone Therapy		
All invasive xnmsc	10.90%	16.83%
Breast	39.72%	61.57%
Prostate	37.69%	58.09%
% of Cases treated with Brachytherapy		
All invasive xnmsc	1.05%	0.76%
Breast	0.10%	0.08%
Prostate	2.17%	1.97%
% of Cases treated with Watch & Wait/Active Monitoring		
All invasive xnmsc	3.60%	N/A
Prostate	11.13%	N/A
% of Cases treated with Palliative Care		
All invasive xnmsc	4.42%	6.83%
Specific cohorts where treatment completeness data is expected (%)		

	UKIACR average	Northern Ireland
% of children and young adults (0-24 group) with cancer & underwent any treatment	81.29%	76.23%
% of all stage 1 cancer patients (exc. Brain and CNS tumours) who received any treatment	83.23%	74.19%
% of men under 60 with prostate cancer & received hormone treatment	19.26%	31.90%
% of men under 60 with cancer (C00-C97 exc. C44) & received hormone treatment	3.15%	5.49%
% of women under 60 with breast cancer & received hormone treatment	29.18%	51.91%
% of all haematological cancer patients who received any treatment	51.42%	28.47%
Quality of treatment data		
Surgery (denominator - all tumours known to be treated with surgery, first recorded surgery for that tumour):		
Date of surgery known	100.00%	100.00%
Trust / hospital of surgery known	99.81%	100.00%
Type of surgery known (OPCS4 code)	100.00%	100.00%
Teletherapy (denominator - all tumours known to be treated with teletherapy , first recorded teletherapy treatment for that tumour):		
Date of teletherapy known	99.95%	100.00%
Trust / hospital of teletherapy known	99.96%	100.00%
Fractions and dose known	100.00%	100.00%
Chemotherapy (denominator - all tumours known to be treated with chemotherapy, first recorded chemotherapy treatment for that tumour):		
Date of chemotherapy known	99.94%	100.00%
Trust / hospital of chemotherapy known	99.97%	100.00%
Drug name or regimen known	78.41%	58.19%
Radiotherapy (denominator - all tumours known to be treated with radiotherapy, take the first recorded radiotherapy event for that tumour):		
Date of radiotherapy known	99.97%	100.00%
Trust / hospital of radiotherapy known	99.97%	100.00%

	UKIACR average	Northern Ireland
Completeness of the dataset (%) - Breast screening information		
Breast cancer - % screen detected for ages 50-64 (data 2014)	40.49%	52.13%
Breast cancer - % screen detected for ages 50-64 (last year, 2013)	44.27%	48.12%
Breast cancer - % with full screening history for ages 50-64 (data 2014)	77.17%	98.82%
Breast cancer - % with full screening history for ages 50-64 (last year, 2013)	86.33%	98.90%
Completeness of the dataset (%) - Cervical screening information		
Cervical cancer - % screen detected for ages 25-60 (data 2014)	30.45%	28.13%
Cervical cancer - % screen detected for ages 25-60 (last year, 2013)	34.40%	22.62%
Cervical cancer - % with full screening history for ages 25-60 (data 2014)	70.33%	100.00%
Cervical cancer - % with full screening history for ages 25-60 (last year, 2013)	88.98%	100.00%
Completeness of the dataset (%) - Bowel screening information		
Bowel cancer - % screen detected for ages 60-69 (data 2014)	22.66%	N/A
Bowel cancer - % screen detected for ages 60-69 (last year, 2013)	25.22%	26.49%
Bowel cancer - % with full screening history for ages 60-69 (data 2014)	76.95%	N/A
Bowel cancer - % with full screening history for ages 60-69 (last year, 2013)	90.55%	99.70%
Completeness of the dataset (%) - stage complete by cancer site groups summary (persons)		
All invasive xnmsc	63.50%	80.0%
All xnmsc 0-24	N/A	N/A
All xnmsc 25-59	N/A	N/A
All xnmsc 60-79	N/A	N/A
All xnmsc 80+	N/A	N/A
Haematology	32.60%	66.6%
Head and Neck	58.55%	94.5%
Lower GI	77.70%	89.6%
Upper GI	58.91%	64.4%

	UKIACR average	Northern Ireland
HPB	56.44%	72.5%
Trachea, Bronchus & Lung	75.66%	91.2%
Melanoma	59.38%	98.0%
Breast	83.02%	93.3%
Cervix	73.33%	93.8%
Other Female Genitals	64.06%	88.1%
Prostate	73.75%	86.2%
Kidney	70.15%	92.3%
Bladder	58.76%	85.9%
Brain and CNS	N/A	N/A
Thyroid and other endocrine glands	57.31%	98.6%
CUP	N/A	N/A
Other invasive cancer	41.84%	66.0%
Breast in situ	N/A	N/A
Cervix in situ	N/A	N/A
Other tumours	N/A	N/A
Non-Melanoma Skin Cancer	11.26%	36.7%
Completeness of the dataset (%) - grade complete by cancer site groups summary (persons)		
All invasive xnmsc	47.59%	52.9%
All xnmsc 0-24	25.33%	23.8%
All xnmsc 25-59	52.64%	59.8%
All xnmsc 60-79	52.54%	56.4%
All xnmsc 80+	35.71%	34.3%
Haematology	15.97%	5.0%
Head and Neck	61.10%	62.1%
Lower GI	62.69%	38.5%

	UKIACR average	Northern Ireland
Upper GI	60.62%	66.6%
HPB	23.88%	28.4%
Trachea, Bronchus & Lung	24.94%	30.8%
Melanoma	0.35%	0.0%
Breast	76.86%	93.5%
Cervix	68.31%	72.8%
Other Female Genitals	64.15%	80.1%
Prostate	65.08%	87.0%
Kidney	56.46%	59.0%
Bladder	72.17%	84.8%
Brain and CNS	75.18%	83.9%
Thyroid and other endocrine glands	10.20%	15.3%
CUP	22.07%	17.4%
Other invasive cancer	21.43%	25.3%
Breast in situ	30.34%	N/A
Cervix in situ	5.56%	N/A
Other tumours	21.46%	N/A
Non-Melanoma Skin Cancer	18.13%	0.8%

Appendix F – Requests for Information

The NICR has provided data and information for 238 requests in 2015, 103 (43%) general requests and 135 (57%) genetic requests (excluding local genetic requests) (Figure 4). A nurse from the Medical Genetics department takes care of local genetic requests. In the past year she responded to 269 genetic requests to provide information to local genetics councillors. In 2015, 99% of general requests for information were completed within the recommended 20 working days and 99% of genetic requests for information were completed within the recommended 10 working days (Figure 5). 37% of general requests were received from non-specific sources with 20% from charities followed by requests from academic research, DHSS and Trust (Figure 6). On average general requests took 106 minutes to complete but ranged from 1 minute to 720 minutes and genetic requests took 16 minutes to complete however ranged from 5 minutes to 40 minutes (not shown). 82% of general requests were received via email (Figure 7) though 95% of genetic requests were received by letter (not shown).

Figure 4: General and Genetic Requests received 2015

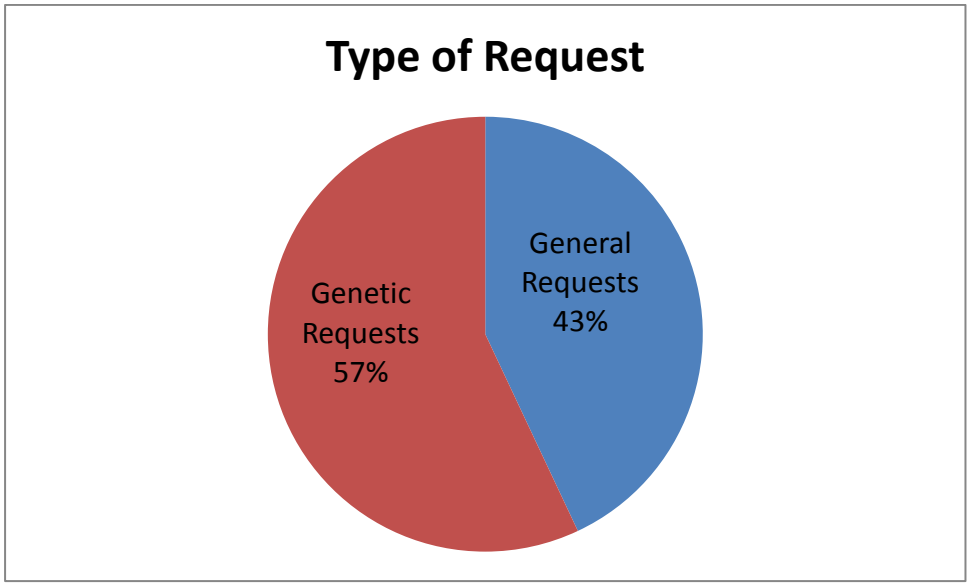


Figure 5: Percentage of requests completed within agreed timeframe

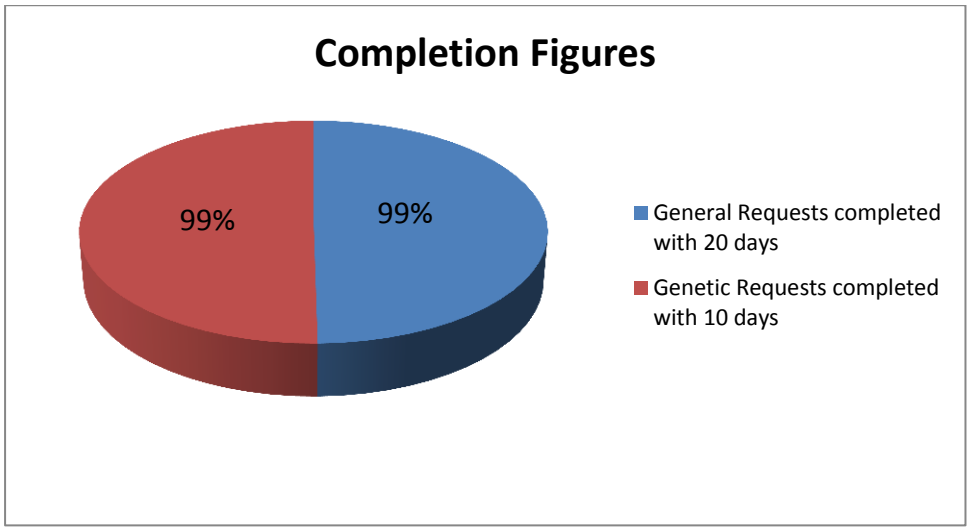


Figure 6: Source of Request – General

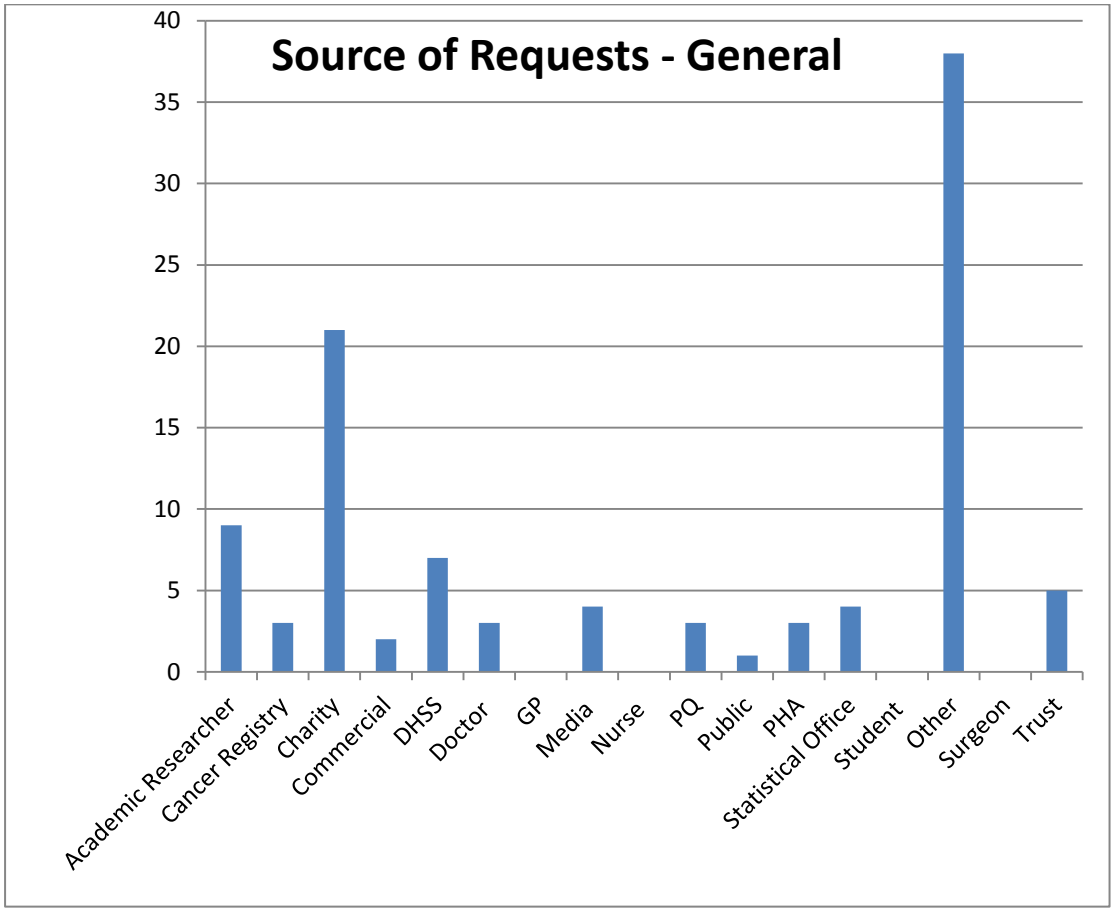


Figure 7: Method of Communication from Requestor – General Requests

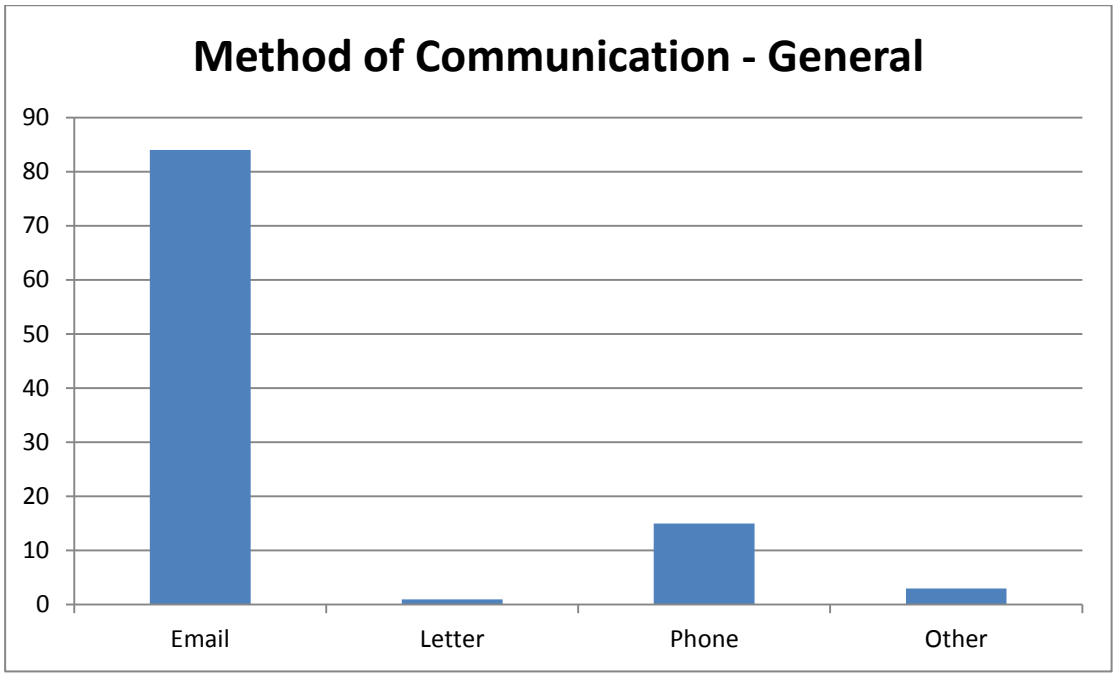


Figure 8: Query Type/Cancer Site – Genetic Requests

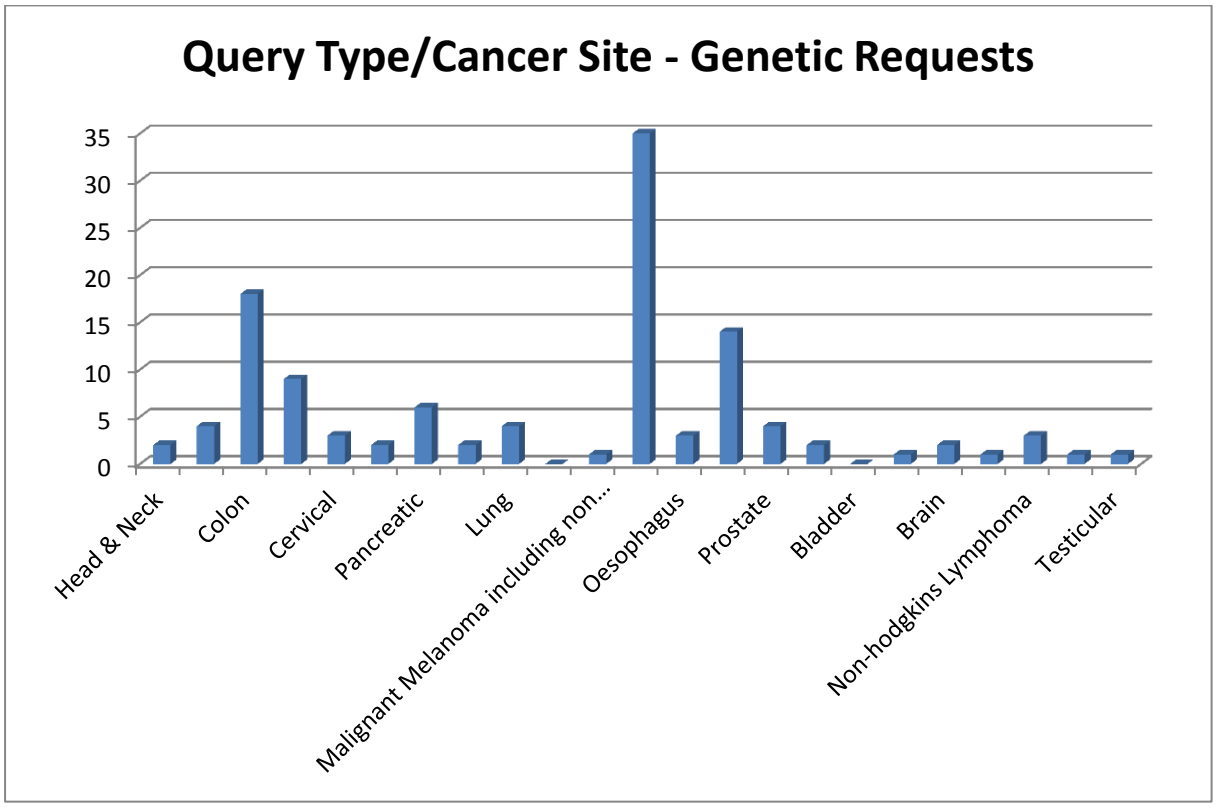
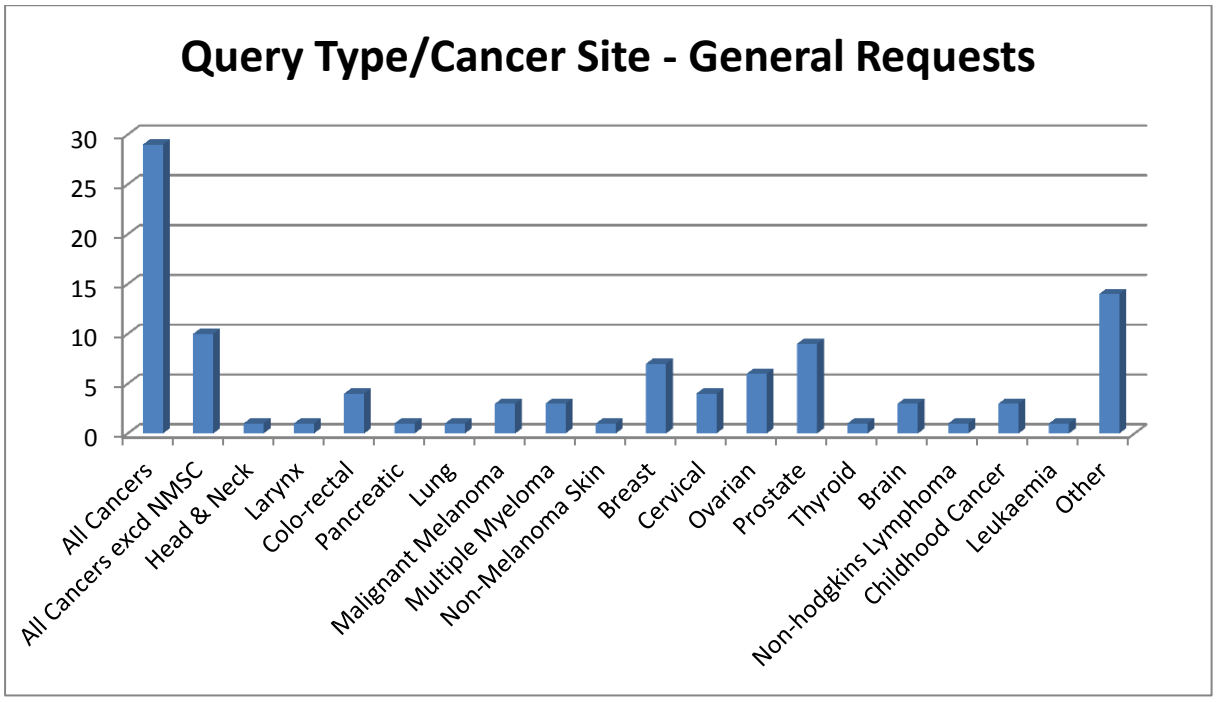


Figure 9: Query Type/Cancer Site – General Requests



In the past year the N. Ireland Cancer Registry has completed 238 requests for information. Table 8 shows a list of general requests (103) and their source which reflect the complexity of the work required to meet these within designated timescale of 20 working days.

Table 8: General Requests for Information 2015

Request Reference	Type of Requester	Date Action Received	Information Required
576	media	06/01/2015	Wants information in the LGD report by Electoral council.
578	charity	06/01/2015	Under 24 years of age
581	dhss	13/01/2015	Information on rates in East Antrim, and possible reasons
582	charity	14/01/2015	Wants all cancers by country
583	PQ	14/01/2015	HPV related cancers
584	charity	16/01/2015	Provided malignant and benign brain tumour information
585	PQ	19/01/2015	Wants number of people diagnosed with cancer in each of the last ten years, for common cancer types
589	dhss	22/01/2015	Differing rates of success of cancer treatment and diagnosis in each Trust
591	PQ	28/01/2015	Incidence rates by PC
593	PQ	02/02/2015	Wants survival rates for as many cancers as possible
595	Trust	04/02/2015	Incidence and rates of leukaemia, lymphoma and myeloma by sex and Trust of residence
596	Statistical Office	04/02/2015	Incidence and mortality by sex, age, deprivation/unemployment/education for selected cancer sites
601	PQ	10/02/2015	Number of women diagnosed in Fermanagh and South Tyrone
602	PQ	11/02/2015	Incidence of prostate cancer in Fermanagh and South Tyrone over last three years
603	PQ	13/02/2015	
613	PQ	23/02/2015	rates by age group

Request Reference	Type of Requester	Date Action Received	Information Required
616	dhss	12/02/2015	by stage
617	Trust	25/02/2015	Prevalence of cancer in western trust
621	charity	18/03/2015	Prevalence of incurable prostate cancer
630	charity	18/03/2015	Mortality from non-malignant cancers
632	public	18/03/2015	Cluster analysis of cancer in Lisbellaw. Three areas investigated plus cancer types in each area provided
634	Statistical Office	23/03/2015	malignant and benign tumours
637	PQ	10/04/2015	Incidence of breast cancer by sex and year - last five years. Plus background notes
638	Cancer Registry	07/04/2015	Incidence and mortality - numbers and age-standardised rates in 2000 and 2012 for all cancer types
639	charity	13/04/2015	Incidence and prevalence of gynaecological cancers by type in 2013
640	charity	13/04/2015	Prevalence of cancer by Local Government District
643	PHA	16/04/2015	Eurocare survival results
645	dhss	20/04/2015	Checking of CMO cancer survival briefing
647	PQ	20/04/2015	Number of sarcomas over last five years plus background notes
648	Statistical Office	16/04/2015	Annual NINIS data
649	PQ	22/04/2015	Cluster check for Kilkeel. All cancers, leukaemia and brain tumours. Kilkeel town and kilkeel plus surrounding area.
650	charity	19/03/2015	Annual CRUK extract
662	PQ	27/05/2015	Number of cases in Northern Ireland who have been diagnosed with prostate cancer in each of the last five days and any accompanying background notes.
663	dhss	01/06/2005	Word versions of predictions reports
664	Academic researcher	01/06/2015	Number of annual cases diagnosed with HPV related cancer sites.

Request Reference	Type of Requester	Date Action Received	Information Required
665	charity	01/06/2015	Using the data on brain tumours, provided a summary page on the statistics in the form suitable for lay person for conference.
669	Statistical Office	15/06/2015	To review a table of incidence of lung cancers in NI by sex and ensure it was correct and that the appended footnotes were also satisfactory.
674	Academic researcher	22/06/2015	Figures on ovarian cancer in North and South of Ireland
675	charity	23/06/2015	Most recent information on children and young adults diagnosed with cancer in Northern Ireland
679	PQ	25/06/2015	Survival from ovarian cancer over time. UK comparisons
680	Trust	24/06/2015	Information on number of Hodgkin's and non-Hodgkin's lymphomas in recent years and number and % of those who were staged.
681	charity	01/07/2015	Information on cancer in the elderly and by deprivation
682	Commercial	02/07/2015	Number of colorectal cancers by stage and by stage by trust area
684	charity	29/06/2015	Information on incidence of DCIS and invasive breast cancer and metastatic breast cancer by age, trust and LGD
685	charity	06/07/2015	Information on statistics on bowel and breast cancer
686	Academic researcher	07/07/2015	Whether anyone has ever opted out of the Northern Ireland Cancer Registry- for application
687	dhss	08/07/2015	Trends in prostate and ovarian cancer
688	Doctor	09/07/2015	Incidence and prevalence figures for Myeloma by patient age <70 and >70 years
690	charity	15/07/2015	Wanted to know if children who relapse with different cancer diagnosis than the original are captured in the registry
692	Academic researcher	22/07/2015	5-year survival in patients with ovarian cancer and deaths.

Request Reference	Type of Requester	Date Action Received	Information Required
694	charity	30/07/2015	The most up-to-date figure for prevalence in Northern Ireland.
695	Trust	29/07/2015	Number of cases from 2009-2013 of breast cancer by subtypes ie lobular, ductal etc. And data on mortalities in this period as well
704	PQ	14/08/2015	Number of cases of childhood cancer in each of the most recent 3 years by trust
708	charity	18/08/2015	Prevalence of all cancers (ex NMSC) by Assembly Area of current residence
712	Academic researcher	20/08/2015	Incidence of malignant melanoma and non-melanoma skin cancer for last 20 years. Also incidence of NMSC broken down by BCC and SCC
713	Academic researcher	21/08/2015	Number of cases of squamous cell carcinoma by age band and sex, Whether cases with SCCs reflect individual patients or if the incidence potentially has multiple records for each person, Incidence of NMSCs (only SCCs) but with one record per patient.
715	Cancer Registry	17/08/2015	Information of Breast cancer surgery for patients diagnosed in 2013
716	Academic researcher	24/08/2015	poster presentation of prevalence and predictors of procedure related distress in men undergoing prostate biopsy
717	charity	24/08/2015	5 year survival for colorectal cancer by health trust and latest bowel screening uptake rates by health trust
718	PQ	20/08/2015	Aggregated incidence data by site (lung, nmsc, other), year, 5 year age, sex and SOA of residence
719	charity	20/08/2015	Incidence and prevalence in North Down & Ards LGD by tumour site

Request Reference	Type of Requester	Date Action Received	Information Required
720	charity	28/08/2015	The date for which NICR mortality data for 2014 would be published
724	charity	02/09/2015	Criteria on screening of bowel, breast and cervical cancers in Northern Ireland and the information we hold
725	charity	04/09/2015	When the 2014 mortality statistics will be published
726	charity	04/09/2015	Incidence of cancer in males (excl NMSC)
727	Trust	07/09/2015	Number of cases and average in recent 5 years of cancers in children and young adults
728	Academic researcher	04/09/2015	Survival time by 2 and 6 years of crc patients dx in 1996, 2001 % 2006 using audit data
735	Media	08/09/2015	Information on key stats on pancreatic cancer
737	PHA	25/09/2015	Prevalence of cancer as of 31st July 2012 in Northern Ireland of people aged 18 years and over.
738	PQ	28/09/2015	Information on where to find incidence and survival statistics on cancer in NI and also treatment and screening data.
738	PQ	29/09/2015	Screening and treatment data
741	Commercial	30/09/2015	Incidence of Oropharyngeal, Anal and Penile cancer (2011-2013) by 5 year age group.
744	Doctor	30/09/2015	Data on incidence, survival trends on Larynx cancer.
746	charity	01/10/2015	Incidence and prevalence in Antrim & Newtownabbey LGD by cancer site
752	Other	09/10/2015	Statistics on occupational exposures and cancer incidence/ mortality
753	Doctor	18/09/2015	Overview of incidence and incidence trends and geographical variation of thyroid cancer in Northern Ireland. Also staging and morphology data

Request Reference	Type of Requester	Date Action Received	Information Required
754	Commercial	07/10/2015	Incidence of Head and Neck cancers (C00, C01, C02, C03, C04, C05, C06, C09, C32) in Males by age
761	Academic researcher	20/10/2015	Request if possible to break down myeloma numbers by category i.e. Smouldering myeloma, active and refractory myeloma.
762	charity	20/10/2015	Number of ovarian cancer cases in NI in 2013. Also inquired about locations for treatment of ovarian cancer and independent drug funding. Information on central hospital for treatment of ovarian cancer and on independent funding requests in NI.
764	dhss	19/10/2015	Incidence, Mortality and survival for All cancers excluding NMSC in patients diagnosed before age 75 years
767	PQ	22/10/2015	Breast Cancer Incidence, Mortality, Prevalence and Survival and proportion of patients diagnosed with Breast cancer in NI that receive treatment
779	charity	02/11/2015	To check age bands that were provided for a previous request
782	charity	02/11/2015	Information on where/ who provides the mortality data for the official statistics
784	DHSS	03/11/2015	All age incidence for all cancers excluding NMSC
785	Other	02/11/2015	Incidence and prevalence of cancer among men and women of working age. Age-standardised incidence rate trend of cancer among men and women of working age.
786	Other	03/11/2015	Incidence of cancer in Newry, Mourne & Down by new electoral wards - by sex, age, cancer type

Request Reference	Type of Requester	Date Action Received	Information Required
787	Doctor	05/11/2015	Review data and interpretation of incidence rates etc of thyroid cancer for presentation
790	Cancer Registry	09/11/2015	Average number of cases of kidney, bladder and prostate cancers by trust.
791	charity	12/11/2015	Number of cases during 1993-2013 of non-malignant cancers. Explanation as to why 2013 data is lower than 2012 for cervix in situ
796	Other	10/11/2015	Information on Location of Treatment (excluding Belfast Cancer Centre and Royal Children's Hospital) for Patients diagnosed with cancer between the ages of 14-25 years
797	charity	17/11/2015	Update of one- year survival for patients diagnosed with All cancers excluding NMSC (2001-2008) by LGD, AA and HSC trust for CRUK website.
798	charity	09/11/2015	CRUK request for deaths by 5-year age group, sex and 4th digit ICD 10 code.
801	PHA	01/12/2015	Number of cases of cervical cancer and deaths during 2004-2013 in women <25 and 25=29
802	PHA	02/12/2015	Average cases of cervical cancer by two age groups before and after introduction of new screening age in 2011
806	Media	04/12/2015	Number of people with multiple primary cancers in NI
807	charity	02/12/2015	Number of deaths by 4th digit icd code for each year of 2011-2013
808	Academic researcher	13/11/2015	Data for CRUK's cancer policy report
815	Charity	26/11/2015	Prevalence of people living with cancer by sex, age at dx, age at censor, tumour site, year of diagnosis, years from diagnosis and year of birth.

Request Reference	Type of Requester	Date Action Received	Information Required
817	charity	17/12/2015	Descriptions in layman terms for the official statistics provided by the Northern Ireland Cancer Registry
821	Academic researcher	02/12/2015	Melanoma Mortality 1984-2011 by year of death, sex and 5 year age category.
822	Other	24/11/2015	Cancer Incidence and Prevalence for those of working age (16-59 years for females and 16-64 years for males) by Cancer site
823	Other	11/12/2015	Further Information for working support request (24.11.2015)- Incidence and Prevalence by cancer site for patients of all ages
824	Cancer Registry	10/12/2015	Breast cancer incidence 2012 by age and stage (0-39 years, 40-49 years, 50-64 years, 65-69 years, 70+ years) for screened and non-screened patients

Appendix G: N. Ireland Cancer Registry Reports and Publications

(available via our web page www.qub.ac.uk/nicr)

1 January 2015/31 March 2016 Peer Reviewed Publications

1. Lawler M, **Gavin A**, Salto-Tellez M, Kennedy RD, Van Schaeybroeck S, Wilson RH, Harkin DP, Grayson M, Boyd RE, Hamilton PW, McArt DG, James J, Robson T, Ladner RD, Prise KM, O'Sullivan JM, Harrison T, Murray L, Johnston PG, Waugh DJ. Delivering a research-enabled multistakeholder partnership for enhanced patient care at a population level: The Northern Ireland Comprehensive Cancer Program. Cancer. 2015 Dec 22. doi: 10.1002/cncr.29814. [Epub ahead of print] (IF 5.068)

2. Rose PW, Rubin G, Perera-Salazar R, Almberg SS, Barisic A, Dawes M, Grunfeld E, Hart N, Neal RD, Pirotta M, Sisler J, Konrad G, Toftegaard BS, Thulesius H, Vedsted P, Young J, Hamilton W, The **ICBP Module 3 Working Group* (*includes Dr Anna Gavin**). Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. BMJ Open 2015;**5**:e007212 doi:10.1136/bmjopen-2014-007212 (IF 2.271)

3. Hajdarevic S, Hvidberg L, Lin Y, **Donnelly C**, **Gavin A**, Lagerlund M, Pedersen AF, Rasmussen BH, Runesdotter S, Vedsted P, Tishelman C. Awareness of sunburn in childhood, use of sunbeds and change of moles in Denmark, Northern Ireland, Norway and Sweden. European Journal of Public Health DOI: http://dx.doi.org/10.1093/eurpub/ckv112 ckv112 First published online: 16 June 2015 (IF 2.591)

4. Coleman HG, Loughrey MB, Murray LJ, Johnston BT, **Gavin AT**, Shrubsole MJ, Bhat SK, Allen PB, McConnell V, Cantwell MM. *Colorectal cancer risk following adenoma removal: a large prospective population-based cohort study*. Cancer Epidemiol Biomarkers Prev (2015) 24(9):1373-80*. Epub June 16. (IF 4.125)*

5. Anderson L, O'Rorke M, Wilson R, Jamison J, **Gavin A**; Northern Ireland HPV Working Group. HPV prevalence and type-distribution in cervical cancer and premalignant lesions of the cervix: A population-based study from Northern Ireland. J Med Virol [Epub ahead of print] 2015 Dec 17. doi: 10.1002/jmv.24447 (IF 2.347).

6. Crocetti E, Mallone S, Eid Robsahm T, **Gavin A**, Agius D, Ardanaz E, Chirlaque Lopez MD, Innos K, Minicozzi P, Borgognoni L, Pierannunzio D, Eisemann N and the EUROCARE-5 Working Group. *Survival of patients with skin melanoma in Europe*

increases further: Results of the EUROCARE-5 study. European Journal of Cancer 51: Issue 15; October 2015, 2179–2190; doi:10.1016/j.ejca.2015.07.039 (IF 5.417).

7. Rossi S, Baili P, Capocaccia R, Caldora M, Carrani E, et al and the **EUROCARE-5 Working Group**. *The EUROCARE-5 study on cancer survival in Europe 1999–2007: Database, quality checks and statistical analysis methods.* European Journal of Cancer 51: 15; October 2015, 2104–2119; doi:10.1016/j.ejca.2015.08.001

8. 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.* Accepted by Supportive Care in Cancer November 2015.

9. Anderson LA, Tavilla A, Brenner H, Luttmann S, Navarro C, **Gavin AT**, Holleczek B, Johnston BT, Cook MB, Bannon F, Sant M. *Survival for oesophageal, stomach and small intestine cancers in Europe 1999–2007: Results from EUROCARE-5.* EJC 2015 Volume 51, Issue 15, Pages 2144–2157.
DOI: http://dx.doi.org/10.1016/j.ejca.2015.07.026. October 2015.

10. Santin S, Murray L, Prue G, **Gavin A**, Gormley G, Donnelly M. *Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors.* European Journal of Oncology Nursing 19(2015) 336-342 Aug 15.

11. Drummond FJ, **Kinnear H**, **Donnelly C**, O'Leary E, O'Brien K, Burns RM, **Gavin A**, Sharp L. Establishing a population-based patient-reported outcomes study (PROMs) using national cancer registries across two jurisdictions; The Prostate Cancer Treatment, your experience (PiCT*ure)* Study. *BMJ Open* 2015;**5**:e006851 doi:10.1136/bmjopen-2014-006851 Apr 15.

12. O'Leary, E, Drummond FJ, **Gavin A**, **Kinnear H** and Sharp L. Psychometric evaluation of the EORTC QLQ-PR25 questionnaire in assessing health-related quality-of-life in prostate cancer survivors: a curate's egg. Qual Life Res DOI 10.1007/s11136-015-0958-y 20 Mar 2015.

13. **Kearney TM, Donnelly C, Kelly JM, O'Callaghan EP, Fox CR, Gavin AT**. Validation of completeness and accuracy of the Northern Ireland Cancer Registry. Cancer Epidemiol. 2015 Jun;39(3):401-4. doi: 10.1016/j.canep.2015.02.005. Epub 12 Mar 2015.

14. Allemani C, Weir HK, Carreira H, Harewood R, Spika D, Wang X, **Bannon F**, Ahn JV, Johnson CJ, Bonaventure A, Marcos-Gragera R, Stiller C, Silva GAE, Chen W, Ogunbiyi

OJ, Rachet B, Soeberg MJ, You H, Matsuda T, Bielska-Lasota M, Storm H, Tucker TC, Coleman MP, the **CONCORD Working Group**. Global surveillance of cancer survival 1995–2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2). The Lancet Vol 385 No. 9972 14 Mar 2015 DOI: http://dx.doi.org/10.1016/S0140-6736(14)62038-9.

15. Quaife SL, Winstanley K, Robb KA, Simon AE, Ramirez AJ, Forbes LJL, Brain KE, **Gavin A**, Wardle J. Socioeconomic inequalities in attitudes to cancer: an International Cancer Benchmarking Partnership study. Eur J Cancer Prev. 2015 May;24(3):253-60. doi: 10.1097/CEJ.0000000000000140.

16. **Gavin AT**, Drummond FJ, **Donnelly C**, O'Leary E, Sharp L, **Kinnear HR**. Patient reported "ever had" and "current" long term physical symptoms following prostate cancer treatments. BJU Int. 2015 Jan 18. doi: 10.1111/bju.13036. [Epub ahead of print] was the featured article of the month and attracted the editorial http://www.bjuinternational.com/article-of-the-week/editorial-hot-topic-of-cancer-survivorship-and-the-seven-deadly-sins/. It also has an accompanying short video summarising the study available at http://www.bjuinternational.com/videos/patient-reported-long-term-physical-symptoms-after-prostate-cancer-treatments/

17. Drummond FJ, **Kinnear H**, O'Leary E, **Donnelly C, Gavin A**, Sharp L. Long-term health-related quality of life of prostate cancer survivors varies by primary treatment. Results from the PiCTure (Prostate Cancer Treatment, your experience) study. J Cancer Surviv. 2015 Jun;9(2):361-72. doi: 10.1007/s11764-014-0419-6. Epub 7 Jan 2015.

2015/16 Reports

1. **Cairnduff V, Gavin A.** Monitoring care for female breast cancer patients in Northern Ireland diagnosed 2012 (with comparisons to 1996, 2001 and 2006). N. Ireland Cancer Registry, QUB 2016, 110 pages.

2. **Donnelly D**. Cancer incidence trends 1993-2013 with projections to 2035. May 2015.

3. **Cairnduff C, Fitzpatrick D, Donnelly C, Blaney J, Gavin A**. Dying with Cancer: Perspectives of Bereaved Relatives/Friends. May 2015.

2015/16 Chapters in Books

1. McKinley J, Ofterdinger U, Palmer S, Jackson C, **Gavin A**. & Fogarty D. 2015 *Tellus.* Young, M. (ed.). Combining environmental and medical datasets to explore potential associations between environmental factors and health: Policy implications for human health risk assessments. Royal Irish Academy, 7 p. (Chapter in book)

Appendix H: N. Ireland Cancer Registry attendance at Conferences/ Meetings and Training Courses

Conferences/Meetings

1. All Ireland Cancer Conference – Belfast, 10-13 May 2015
2. Cancer Outcomes Conference – Belfast, 8-10 June 2015
3. UKCRC Conference – Edinburgh, November 2015

Training Courses

1. Anatomy and Oncology for Non-clinicians – 5Staff – March/April 2015
2. Developing for Success – Emotional Intelligence and leading others – 1 Staff - April 2015
3. Anatomy and Oncology for non-Clinicians – 1 Staff - June 2015
4. PHA ABS Breast Audit Day – 3 Staff – Belfast June 2015
5. UKIACR Analyst Group meeting – 1 Staff – London June 2015
6. Electronic NSP Training Course – 1 - June 2015
7. Web Authoring: Introduction to CMS – 1 Staff – July 2015
8. ISO 27001 Certified ISMS lead implementer course – 1 Staff - Manchester 5-7 August 2015
9. UKIACR Analyst Group meeting – 1 Staff - Teleconference September 2015
10. Staff Well Being – Stress Management Workshop – 1 Staff - September 2015
11. Webinar: Lymphoma Webinar- 2 Staff – September 2015
12. Randomised Controlled Trials course – 1 Staff - September 2015
13. UK Biobank in CPH- 1 Staff - September 2015
14. QUB Improving Personal Resilience – 1 Staff - October 2015
15. Intersystems Cache Foundations Course – 1 Staff - Windsor -6-8 October 2015
16. Registration Practices – 3 Staff – October 2015
17. Pathology Reports & Staging – 3 Staff – October 2015
18. Multiple primaries including Haematology – 3 Staff – October 2015
19. Webinar: Cells, Tissue and Cancer – 4 Staff - October 2015
20. Webinar: Lung Cancer Training – 4 Staff- October 2015
21. Webinar: Spread of Cancer – 4 Staff - October 2015
22. Webinar: Breast Cancer Anatomy & Oncology – 4 Staff – October 2015
23. Webinar: Staging & Grading Malignant Tumours – 4 Staff – October 2015
24. Webinar: Clinical Coding of Malignant Neoplasms – 3Staff – October 2015
25. Coding in ICD-O and ICD10 – 2 Staff – October 2015
26. QUB Data Protection (online) 1 Staff – October 2015
27. QUB Diversity Now (online) 2 Staff – October 2015

28. QUB Fire Safety E-Learning course – 2 Staff – October 2015
29. QUB Freedom of Information (online) 2 Staff – October 2015
30. Interval Breast Cancer Workshop – 2 Staff - October 2015
31. Senior Secretarial Skills Programme: Setting Priorities & Meeting Deadlines – 1 Staff – October 2015
32. Senior Secretarial Skills Programme: Working with a Senior Manager – 1 Staff – November 2015
33. Webinar: Hallmarks of Cancer – 1 Staff – November 2015
34. Excel: Introduction to PivotTables using Excel – 1 Staff - November 2015
35. QUB Health & Safety for Computer Users (online) – 2 Staff - November 15
36. Is Cancer Bad Luck seminar by professor Davey Smith – 1 Staff – November 2015
37. Managing a University Social Media Site – 1 Staff – November 2015
38. Introduction to Prezi - 1 Staff - November 2015
39. QUB Health & Safety for Computer Users (online) – 1 Staff – November 2015
40. UKIACR Analyst Group meeting – 1 Staff - Teleconference November 2015
41. CoE Away Day – 1 Staff - November 2015
42. Staff Well Being – Improved Personal Resilience – 2 Staff - December 2015
43. QUB Fire Safety E-Learning course – 2 Staff - December 2015
44. QUB Health & Safety for Computer Users (online) – 3 Staff – December 2015
45. QUB Induction for All New Staff – 2 Staff – December 2015
46. QUB Fire Safety E-Learning course –1 Staff – December 2015
47. QUB Data Protection (online) – 1 Staff – December 2015
48. QUB Diversity Now (online) – 2 Staff – December 2015
49. QUB Welcome & Induction for new staff – 1 Staff – December 2015
50. NICON- Discussion series with Minister Simon Hamilton. Leading Change in Health and Social Care – 1 Staff - December 2015
51. P2P training (3 sessions) – 2 Staff – January 16
52. QUB Freedom of Information (online) – 1 Staff – January 2016
53. QUB Health and Safety for Computer Users (online) – 1 Staff – January 2016
54. Webinar: Colon Cancer Anatomy and Oncology – 4 Staff – January 2016
55. Demographic Methods using Longitudinal and Area-data- 1 Staff - January 2016
56. Clerical Induction: Working in the University – 3 Staff – January 2016
57. Clerical Induction: Written Communication Skills – 3 Staff – January 2016
58. Clerical Induction: Word Processing – 3 Staff - January 2016
59. Senior Secretarial Skills Programme: Effective Minute Taking – 1 Staff – January 2016
60. Training, selection Interviewing – Refresher Training – 2 Staff – January 2016
61. Senior Secretarial Skills Programme: Going the extra mile in Customer Care – 1 Staff – February 2016
62. UKIACR Analyst Group meeting – 1 Staff - February 2016

63. Clerical Induction: Email and Calendar Management – 3 Staff - February 2016
64. Computer Workstation Risk Assessment- 1 Staff - February 2016
65. PRINCE2 Foundation course (3 days) – 1 February 16
66. PRINCE2 Foundation & Practitioner course (5 days) – 1 February 2016
67. Genetics Cancer/Art: Theatre a personal twist of the helix to enhance human health – 1 Staff - February 2016
68. CPH Annual Health & Safety Training – 1 Staff - February 2016
69. Image Guided Radiotherapy distance/online masters module with Sheffield Hallam University evenings/weekends – 1 Staff – January/February 2016
70. National Cancer Registration Service Training Event – 7 Staff – March 2016
71. My Learning Space (Modules; What is Cancer , Cancer Registration, Medical Terminology, Anatomy and Physiology, Diagnostic Tests, Cancer Treatments, MDTs, Brain and Central Nervous System Cancer, Urinary Tract Cancer, Kidney Cancer, Skin Cancer (melanoma and non-melanoma), Penile Cancer, Prostate Cancer, Testicular Cancer, Breast Cancer, Lower Gastrointestinal Tract Cancer, Endometrial and Uterine Cancer, Cervical Cancer, Ovarian Cancer, Placental Cancer, Fallopian Tubes Cancer, External Genitalia Cancer, Respiratory System and Mesothelioma Cancer) – 6 Staff - various dates (not all staff undertook training in all modules)
72. CEHSRG fortnightly meetings – 1 Staff – Journal club

Appendix I: CanStaging access stats to December 2015

Figure 10: CanStaging Access Requests

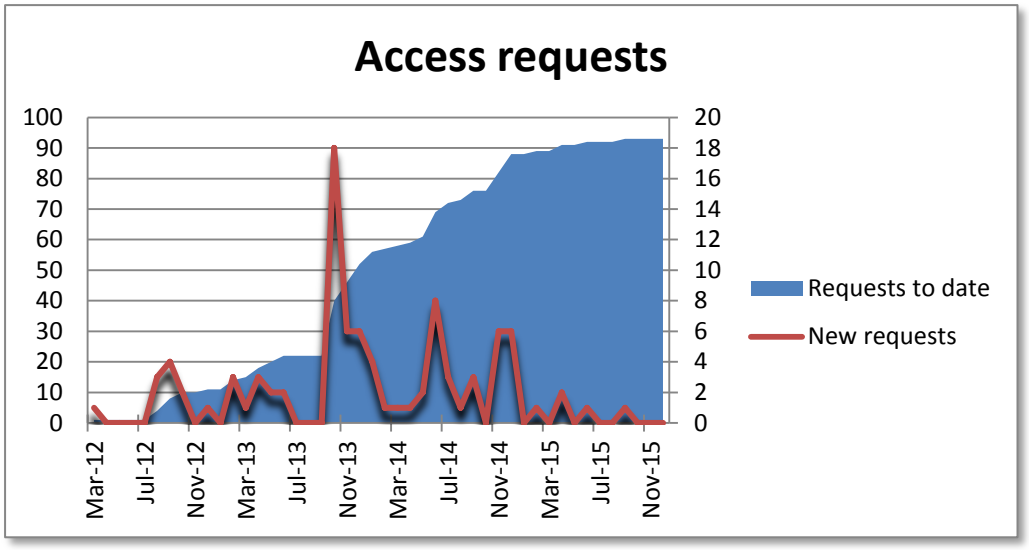
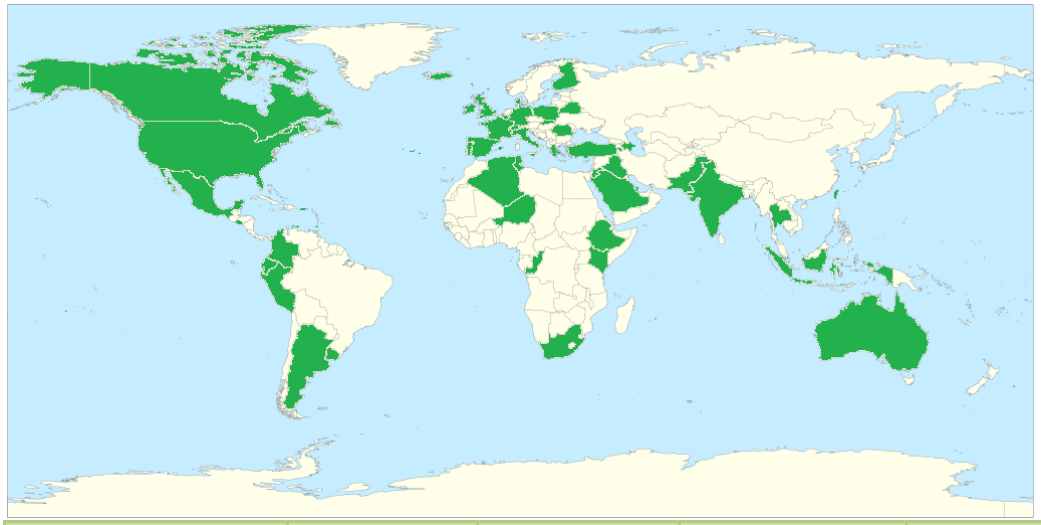


Figure 11: Countries where at least one organisation has requested access



Algeria	Curaçao	Iceland	Nigeria	South Africa
Argentina	Denmark	India	Pakistan	Spain
Australia	Ecuador	Indonesia	Peru	Switzerland
Azerbaijan	El Salvador	Iraq	Poland	Taiwan
Basque Country	Ethiopia	Ireland	Portugal	Thailand
Belarus	Finland	Italy	Puerto Rico	Tunisia
Belgium	France	Jordan	Qatar	Turkey
Canada	Germany	Kenia	Romania	UK
Colombia	Greece	Luxembourg	Saudi Arabia	Uruguay
Congo	Grenada	Mexico	Slovakia	USA

Actual usage

These are estimated values: only when users click the 'Submit' button the cancer site information will be saved to the log, but we have found that most of the users simply transcribe stage information as it appears on screen.

Figure 12: Access to tool by cancer site

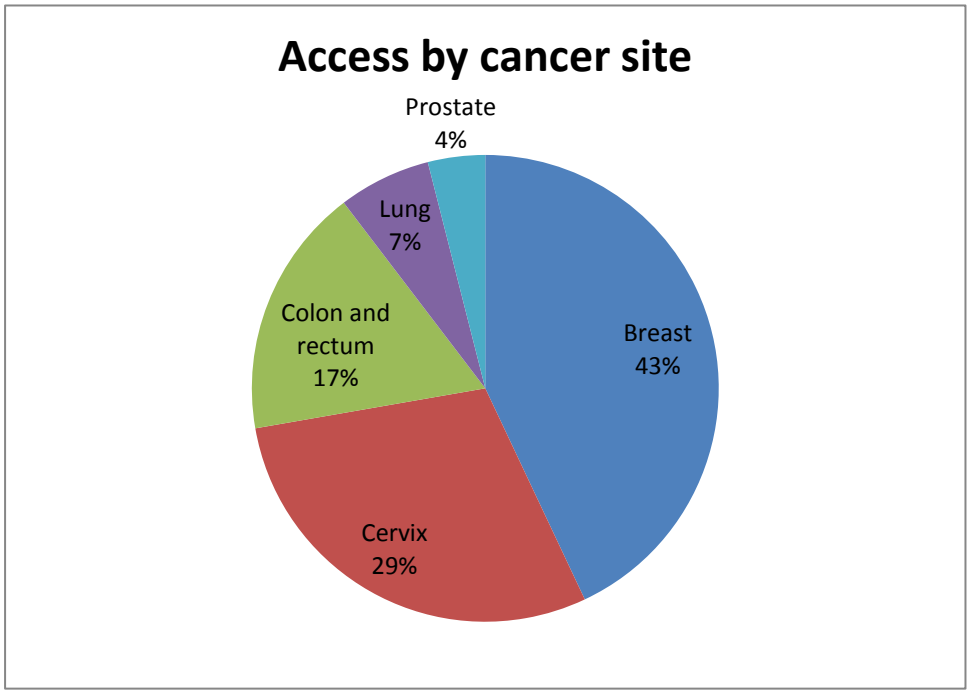
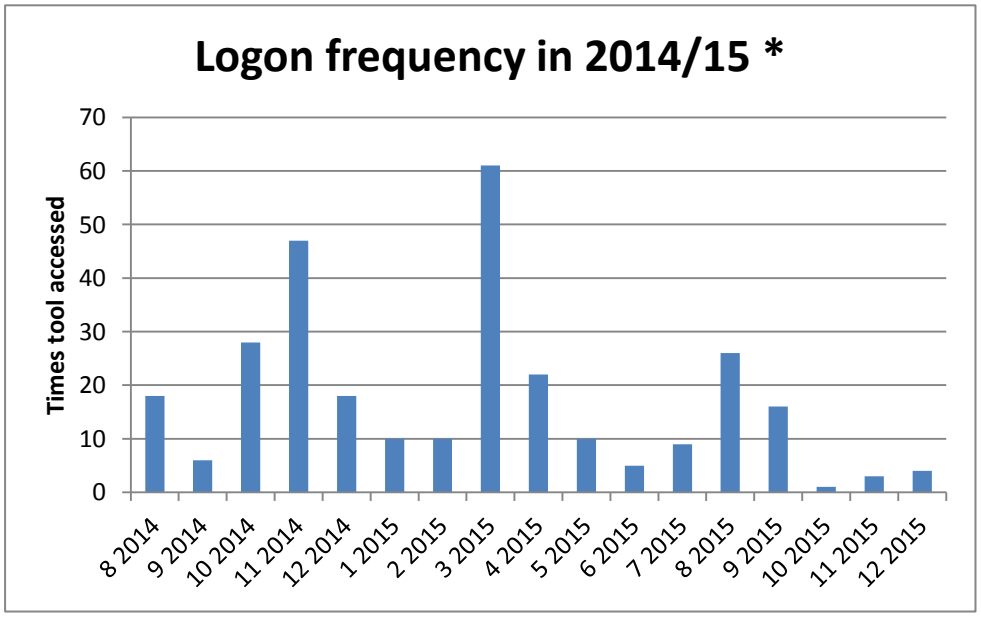


Figure 13: Tool logon frequency in 2014/15



(*) Excluding NICR and IARC access