

NICR Newsletter

COVID-19 Crisis

At the beginning of 2020, the COVID-19 pandemic quickly swept across the world, bringing with it changes to ordinary life that no one ever imagined. On Monday 23rd March 2020 a 'Lockdown' was brought into force in the UK, following in the steps of many countries across the world. This in turn brought huge changes to the world of work with staff now working remotely at home, having regular video calls via Microsoft Teams to keep in touch. A joint effort by the N. I Cancer Registry IT Team and Data Manager in liaison with Health and Social Care Trusts ensured IT systems were established and access to Datasets achieved to enable staff to work from home as if they were in the office. This access also enabled vital analysis of COVID-19 impact statistics to take place. The Registry was also the first department within the University to establish a Remote Working policy. We were also able to launch the official statistics for 2018 cancer cases in N. Ireland on 2nd April as planned. Many thanks to all staff for their help and cooperation adjusting to this 'new normal'.



Also as a result of Lockdown across many countries, National and International Conferences planned were postponed or cancelled and projects/audits also postponed. It is hoped when restrictions are lifted all these plans can proceed. [See pages 2 and 3 for details of effect on cancer.](#)

ISO 27001 re-certification

On the 20/21st February 2020 the external auditor visited the NI Cancer Registry to carry out a re-certification audit. Our certification has been in place for three years and this, being the end of the certification cycle required a full audit of our Information Security Management Systems (ISMS). We're delighted to say that after an extensive audit, observation and interviews with various staff members in the Registry, the auditor recommended that the NICR be recertified for a further 3 years. We received our renewed certificate in April and are now certified to the ISO27001:2013 standard for information security management until June 2023. The certification and internal audit process has proven useful to staff and has heightened awareness of information security risks in the workplace. It has also been useful for applying for grant application and information sharing requests and has received positive recognition from within Queens University and further afield.



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COVID-19 Impact Analysis

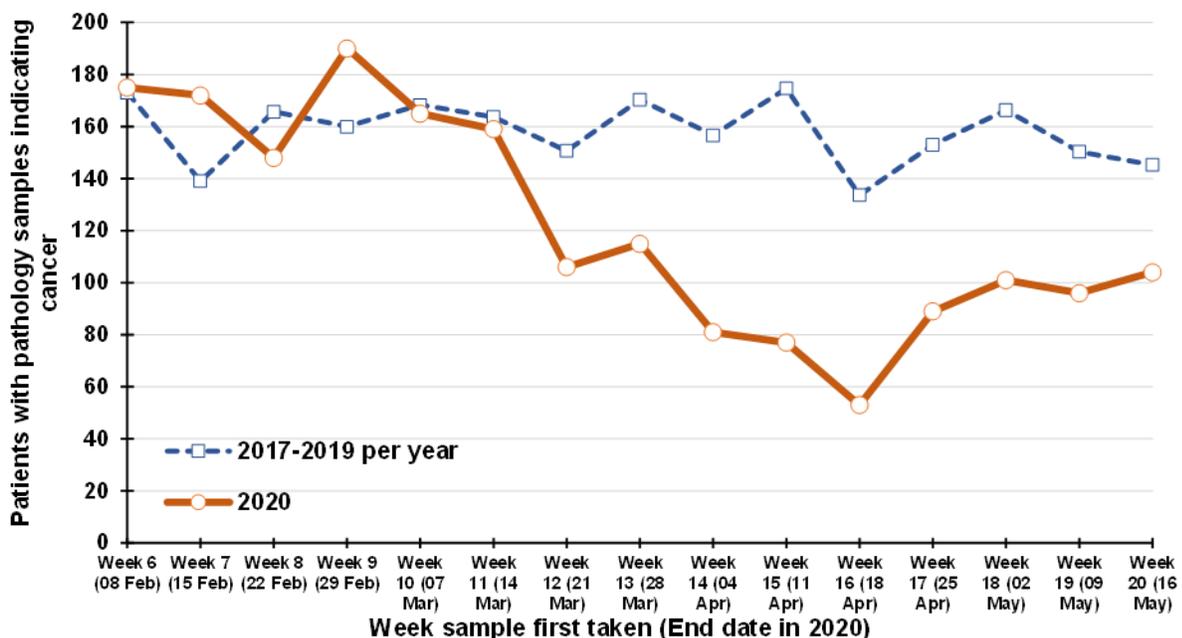
During the last few weeks of March lockdown restrictions began to be put in place in Northern Ireland to help prevent the spread of the COVID-19 virus. Consequently some key cancer services, such as breast and bowel screening, were impacted, while many potential cancer patients did not come forward with symptoms due to concerns over the virus. To evaluate the resulting impact of this lockdown on cancer diagnosis, NI Cancer Registry (NICR) produces a monthly overview of recent trends in the number of patients with pathology samples indicating cancer in 2020. These trends are contrasted with the annual average number of patients with pathology samples indicating cancer during 2017-2019. Data were sourced from the four NHS pathology laboratories in Northern Ireland (Belfast, Altnagelvin, Antrim, Craigavon), which are usually provided to the NICR on a monthly basis.

The May 2020 update highlights the downturn in actual diagnoses of cancer in Northern Ireland since the COVID-19 lockdown. Previous anecdotal reports of the downturn in cancer referrals from GPs during the lockdown period was thus translating into a considerable number of people with cancer not being diagnosed with the disease. Since the beginning of March the number of cancer patients being diagnosed was one third lower than in the previous three years, while in the five weeks up to the 16th May diagnosis was down by 41%. This means that there were an estimated 700-800 people with cancer in Northern Ireland that had not yet been diagnosed with the disease compared to previous years. This potentially has implications for the stage at which these patients may be ultimately diagnosed at, and consequently their survival prospects.

There were, however, some signs of recovery. In the week ending 16th May, diagnosis was down 28% compared to the previous three years (about 40 patients). This was in contrast to the downturns in the weeks ending 11th April (a 56% decrease, 98 patients) and 18th April (a 60% decrease, 81 patients).

As a result of the COVID-19 related changes cancer diagnosis in 2020 has fallen by a third, but by mid-May some signs of improvement were apparent.

Figure 1: Trends in patients with pathology samples indicating cancer (ex NMSC) by week first sample taken



The impact and recovery, however, was not the same for all types of cancer. Prostate cancer diagnosis, which was initially severely impacted by the lockdown, recovered swiftly. Breast cancer and bowel cancer diagnosis, however, remained well below expected levels (54% below previous years for bowel cancer and 56% below previous years for breast cancer). This may in part be related to the impact of the lockdown on screening services. Particularly of concern was the impact on lung cancer diagnosis. While the impact on this cancer has not been as severe as on bowel and breast cancer (lung cancer diagnosis is down 46% in the five weeks up to 16th May), this cancer is a poor survival cancer, with early diagnosis critical to patient survival.

Other variations by patient demographics were evident. Compared to the annual average in 2017-2019 the number of patients with first pathology samples indicating cancer for the same time period in 2020 decreased 32% among males, compared to 49% among females, a difference likely related to cancer type. With regards age group, the decrease was 39% among patients aged 0-69 years and 43% among those aged 70 and older, while reductions were greater in Craigavon (63%) and Antrim (53%) laboratories than in Altnagelvin (39%) and Belfast (32%).

NICR continues to monitor the impact of the lockdown on cancer services, with updates to this data produced by the end of each month.

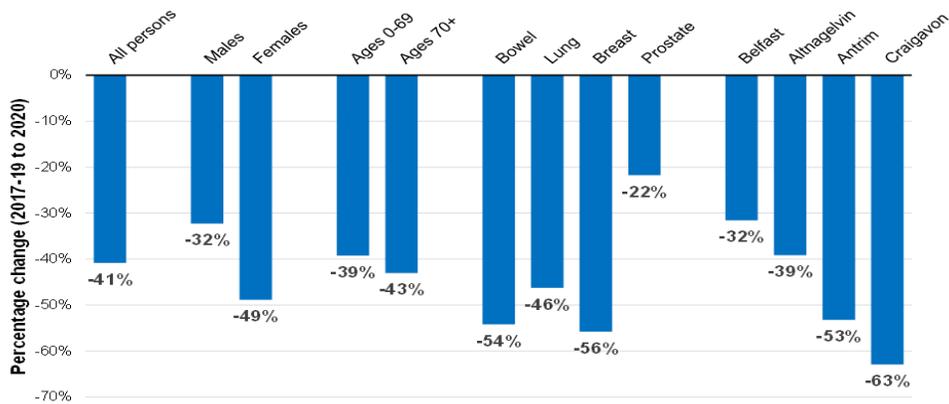


Figure 2: Percentage change in patients between 2017-2019 and 2020 with pathology samples indicating cancer (ex NMSC) first taken in weeks 16-20 of each year (12 Apr - 16 May in 2020)



QUEEN'S UNIVERSITY BELFAST



IMPaCCT study



UNIVERSITY OF ABERDEEN

Investigating the impact of COVID-19 on Caregivers and patients.

The true impact of COVID-19 on some of society's most vulnerable people and their caregivers is being explored through an international survey from researchers at the Northern Ireland Cancer Registry, Queen's University Belfast in collaboration with the University of Aberdeen.

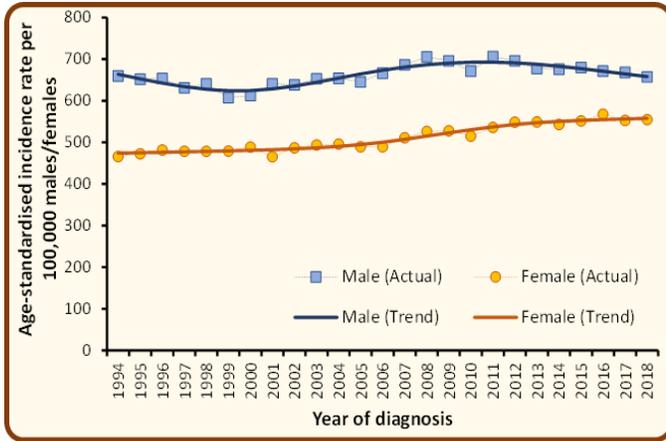
The first survey which closed on 30th June aims to assess the current needs expressed by patients with cancer, precancerous conditions and rare diseases and those who help to care for them.

It is understood that caregivers and patients are experiencing a major impact of COVID-19 on their lives with health services forced to change in order to ensure the safety of patients.

The survey will assess the impact that these and other changes due to the coronavirus pandemic have had on caregivers and patients to help doctors, nurses and other healthcare providers and charitable organisations to identify the best ways to support patients during this time. To date 1,265 cancer patients, 186 patients with a precancerous condition, 437 patients with a rare disease (including some with cancer) and 637 caregivers have participated in the survey. Approximately 90% of participants have agreed to be re-contacted in September 2020 and again in January 2021 to identify the long-term effects of the pandemic.

Official Statistics

Trends in incidence rates of cancer (ex NMSC)



Official Statistics on cancers diagnosed in Northern Ireland during 1993-2018 were published on 2nd April 2020. This release provides details of the number of cancer cases diagnosed each year, trends in incidence rates, incidence for a range of geographic areas, survival trends and prevalence (the number of people alive) for all cancers combined and a wide range of cancer types. Summary fact-sheets of this information along with spreadsheets containing detailed tabular data are available on the NICR web site at www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/

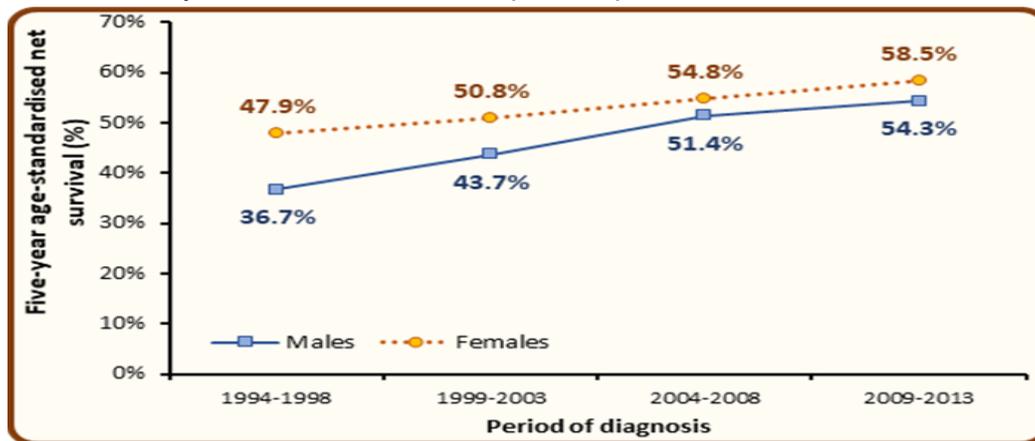
Due to the ageing of the population, cancer incidence continues to increase. However, survival for the disease is better than ever.

Some of the key facts from the release are as follows:

- There were 9,629 (4,810 male, 4,819 female) patients diagnosed with cancer, excluding non-melanoma skin cancer (NMSC), each year during 2014-2018. There were on average 3,823 cases of NMSC diagnosed each year.
- The most common cancers diagnosed were prostate, lung and bowel cancer among men, and breast, lung and bowel cancer among women.
- Between 2009 and 2018 the number of cancer cases (ex. NMSC) increased by 17% for men, and by 20% for women. These increases are largely due to our ageing population.
- After removing the effect of changes over time in the age and size of the population, between 2009-2013 and 2014-2018 cancer incidence rates among males decreased by 3%, while among females they increased by 4%.
- Cancer types with increases greater than 20% in the average number of cases per year between 2009-2013 and 2014-2018 were male kidney cancer, male & female myeloma, male melanoma, male pancreatic cancer, male oesophageal cancer, male & female liver cancer, and female lung cancer. Decreases in the number of cases were observed for female stomach cancer, male bowel cancer, male stomach cancer and cervical cancer.

- Removing the impact of changes in the age distribution and population size for the four most common cancers, between 2009-2013 and 2014-2018:
 - Rates of female breast cancer increased by 5%;
 - Rates of bowel cancer decreased by 14% for men and by 7% for women;
 - Rates of lung cancer decreased by 6% for men but increased by 18% for women;
 - Rates of prostate cancer decreased by 2%.
- Among patients diagnosed with cancer during 2009-2013, one-year net survival after diagnosis was 72%, while five-year net survival was 57%. However, one in five (21%) of patients died within six months of diagnosis.
- Five-year net survival for patients diagnosed between 2009 and 2013 was highest for testicular cancer (96%) and melanoma (94%), but remained poor for liver cancer (13%) and pancreatic cancer (6%). For the most common cancers five-year survival was 83% for female breast cancer, 62% for bowel cancer, 87% for prostate cancer and 12% for lung cancer.

Trends in five-year survival from all cancers (ex NMSC)



- Cancer survival improved significantly between 2004-2008 and 2009-2013, with one-year survival increasing for men from 68% to 71% and for women from 70% to 73%. Five-year survival increased among men from 51% to 54% and among women from 55% to 58%.
- There were significant improvements in five-year survival between 1994-1998 and 2009-2013 for bowel cancer, lung cancer, female breast cancer, prostate cancer, kidney cancer, male oesophageal cancer, uterine cancer, male myeloma, leukemia, and lymphoma.
- Stage at diagnosis remains the biggest factor in cancer survival. For example, five-year survival between late and early stage bowel cancer ranged from 8% to 98%.
- At the end of 2018 there were 65,722 cancer survivors who had been diagnosed with cancer (excluding Non Melanoma Skin Cancer) since 1994 (i.e. over the last 25 years). The most prevalent types of cancer among these survivors were prostate cancer, with 10,938 men living with the disease, and breast cancer, with 16,462 women living with the disease. Follow <http://www.qub.ac.uk/research-centres/nicr/Publications/Factsheets/> to view recent NICR Factsheets.

On-going Research

Pathways to cancer diagnosis: Monitoring variation in the patient journey across Northern Ireland

The report Pathways to a Cancer Diagnosis: monitoring variation in the patient journey across NI, 2012-2016 was published on the 15th January 2020, and provides, for the first time, a comprehensive picture of the different routes by which cancer patients in Northern Ireland (NI) receive their diagnosis.

The report is the culmination of an 18 month project involving researchers from Queen's University Belfast working collaboratively with analysts from the Health and Social Care Business Services Organisation (BSO). Data on all cancer patients diagnosed from 2012-2016 in N. Ireland collected by the Northern Ireland Cancer Registry was linked to in- and out-patient Patient Administration System (PAS) hospital-episode data, and 'red-flag' referral data from the Cancer Patient Pathway System (CaPPS) held in the Honest Broker Service, of BSO, Department of Health NI.

An algorithm developed by the National Cancer Registration and Analysis Service (a part of Public Health England) was used on NI data to work out each cancer patient's most likely 'Route to Diagnosis' by using routine data to work backwards through patient pathways to examine the sequence of events that led to a cancer diagnosis. Through this analysis, eight broad routes were identified and statistics on the percentage of patients diagnosed and their survival were produced. The research was conducted within BSO's Honest Broker research facility.

In addition to routes-to-diagnosis for All Cancers (excluding non-melanoma skin cancer), the report presents information for individual cancer sites (Colorectal, Breast, Lung, Prostate, Cervical, Melanoma) and for groupings of other cancer sites of interest.

Of the 46,068 cancer (excluding non-melanoma skin cancer) patients diagnosed in NI from 2012-2016, one fifth were diagnosed through an emergency route to diagnosis, and had a poor net survival at three years, 23%. The proportion of emergency presentations was higher in deprived areas and among older patients.

The proportions of patients diagnosed via screening (6%) and emergency presentation route to diagnosis (20%) in NI were very similar to England. However, compared to England, NI has greater proportions of patients diagnosed via outpatient and inpatient elective routes, and smaller pro-



Dr Finian Bannon, CPH

portions of red flag and routine GP routes. Further work is required to understand the local factors which might be driving such differences given that, for many patients, their route into secondary care, for whatever condition they may have, will typically begin with a consultation with their GP.

The proportion of patients diagnosed via screen-detected routes-to-diagnosis varied between the cancer sites with NI screening programmes, breast (29%), colorectal (8%), and cervix (24%), but were not different from England. Like England, survival was higher for screen-detected patients (>90%). Fewer cancer patients were diagnosed through screening with increasing levels of deprivation.

Dr Finian Bannon, Principal Investigator on the QUB team, said "The findings of the study will help improve patient outcomes by increasing our understanding of how cancer services are delivered, and how services can be improved."

More detailed breakdowns are available on an interactive tool designed for an internet platform.

The full report and interactive tool is available on the Business Services Organisation's website (<http://www.hscbusiness.hscni.net/services/3102.htm>).

It has been another busy year for the Northern Ireland Barrett's Oesophagus register (NIBR) with the update funded by a Cancer Research UK Career establishment award, continuing at a great pace. Over 35,000 pathology reports from 2013-2018 have been reviewed in the first two years of the grant. In January 2020, the NIBR team said farewell to Mr Sean Morrison as he moved to a new post within the QUB student guidance centre. Sean has made an invaluable contribution to the NIBR update during his 18 months in post and we wish Sean every success in his new role. The team are delighted to welcome Mr Andrew Hamilton who joined the NIBR update team, reviewing pathology reports, in February 2020.

The update of the register will allow Prof Helen Coleman, Dr Victoria Cairnduff and the wider study team to investigate up-to-date trends in diagnoses of Barrett's Oesophagus, low and high grade dysplasia, and oesophageal adenocarcinoma in the modern treatment era, when some patients are now treated with endoscopic therapies.



Prof Helen Coleman

Northern Ireland's Barrett's Register

CRUK Early Detection grants success for Barrett's register researchers

The Barrett's register isn't just a fantastic resource for studying epidemiological disease trends, it is also an invaluable sampling frame for biomarker studies. Thankfully, CRUK agree! Two new studies have been funded through the CRUK Early Detection committee, and are due to start later in 2020.

The first is a one year 'Primer Award' that will investigate a biomarker for the molecular age of Barrett's tissue - it is hoped that this could give a clue as to how long someone may have had Barrett's Oesophagus before they were actually diagnosed with it. This work is being led by Professor Helen Coleman in collaboration with Dr Kit Curtius at Queen Mary University of London, Dr AJ McKnight (CPH) and the Barrett's register research team.

The second is a three year project grant that will investigate biomarkers for progression from Barrett's Oesophagus to oesophageal adenocarcinoma, led by Dr Richard Turkington in conjunction with the Barrett's register team members.

This represents a very welcome investment of over £600,000 from Cancer Research UK into Barrett's Oesophagus Early Detection research in Northern Ireland.

On-going Research

NICR-Macmillan Partnership 2019-2020



The NICR-Macmillan partnership is now in its fifth year. The partnership aims to deliver insightful analysis of Northern Ireland cancer data to support the improved design, testing and implementation of better models of care, to identify gaps and opportunities to enhance data collection and analysis for improved outcomes for people living with and beyond cancer in Northern Ireland. Previous phases of the partnership have involved analysis of routine registration data to assist with evaluation of the Transforming Cancer Follow-up programme for breast cancer patients, developing GP Federation cancer profiles and working towards establishing a method for routinely collecting and reporting on breast cancer recurrence. The Macmillan Cancer Support-NICR partnership report investigating factors associated with emergency admissions in the last year of life for 4,316 people who died from cancer in Northern Ireland in 2015 was launched on 8th August 2019 and is available at (<https://www.qub.ac.uk/research-centres/nicr/Publications/MacmillanNICRPartnership/>)

The findings showed that:

A high use of emergency admissions in the last year of life with almost three quarters of people having at least one emergency admission recorded.

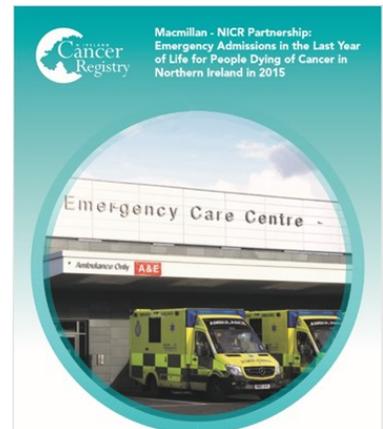
Late diagnosis is an issue with 1 in 9 people (11%) admitted as an emergency on the same day as their cancer diagnosis

- 1 in 6 (17%) people died within 7 days of their last emergency admission - almost all (95%) of these people died in hospital
- Over half (53%) of emergency admissions occurred outside of 'normal working hours': 5pm-9am, Monday to Friday The report Emergency Admissions in the Last Year of Life for People Dying of Cancer in NI in 2015 investigated factors associated with emergency admissions in the last year of life and highlighted a number of concerns relating to frequency of admission, late diagnosis, care planning and preferred place of death
- People who had at least one emergency admission were twice as likely to die in hospital (48% vs 24%). One in six people died within 7 days of their last emergency admission and of these, almost all died in hospital.

The report makes a series of six recommendations to improve person-centered care for cancer patients in their last year of life:

- continuing to promote early detection of cancer
- early identification of patients who are in their last year of life
- additional training for healthcare professionals to improve communication and advance care planning
- establishing a direct point of contact for patients and their carers
- piloting extended hours for the NI Acute Oncology Service
- further development of community-based services

The NICR-Macmillan partnership forms part of a larger UK wide analytical partnership initiative with partnerships established between Macmillan Cancer support and National Cancer Registration and Analysis service (NCRAS) Public Health England, Scottish Cancer Registry and Information Services Division (ISD) and the Welsh Cancer Intelligence and Surveillance Unit (WCISU). In line with this aim and to promote further collaborative working between Cancer Data Analysts/Researchers within in the UK, Macmillan Cancer Support hosted the 'Working together: building an analytical community for cancer care' event in London in September 2019.



The next phase of the partnership (delayed due to COVID-19 expected to start Autumn 2020) will involve, North West Cancer Centre radiotherapy analysis which will look at the impact on patients treated at the new NWCC radiotherapy centre with a focus on demographic differences. Treatable but not curable cancers which will look to identify the incidence of cancers which are treatable but not curable in Northern Ireland, in line with Macmillan guidelines.

Biobank/NICR Partnership

The Northern Ireland Biobank (NIB) is a cancer specific biobank which was awarded full ethical approval in August 2011 (ORECNI Ref: 16/NI/0030) for the collection of surplus tumour and non-tumour control tissues and associated biospecimens from patients with a suspected or confirmed diagnosis of cancer. NIB has two 'strands' to its workflows, namely the prospective and retrospective collections. The NIB prospective collection targets colorectal, breast, prostate, gynaecological, lung, head and neck and haematological malignancies with linkage to robust de-identified clinic pathological data. Donation to the prospective collection is voluntary and requires written informed consent from patients. The retrospective collection relates to the ethical and governance approvals in place to allow NIB to access the NHS tissue pathology diagnostic archives. This allows NIB to retrieve defined cohorts of cancer tissues for ethically approved studies which are anonymised and made available in a timely manner for scientifically sound translational research activities.



The NICR supports the NIB's work by linking anonymised clinical and pathological information stored on the NICR database with samples requested for particular NIB ethically approved studies. All data are examined and extracted in a confidential setting under agreed ethical and governance approvals. Data linkage is achieved via the use of a pseudonymised number; no personal identifiers are ever released to NIB studies.

Since July 2019, the TVO team has provided data on nearly 1000 individual cases for specific dataset requests from the NIB. As seen in the previous working year, we have had multiple requests that have required extraction of recurrence information for particular cohorts of patients including those diagnosed with melanoma, breast, colorectal and lung cancer. These requests highlight the importance of the NICR for the provision of cancer relapse data for clinical research that may help towards improving knowledge about patients who are likely to relapse and aid in the discovery of better diagnostic methods and treatments for recurrences. Other data requested over the year includes smoking & alcohol history as well as tumour details for a cohort of oral cancer cases.

CanStaging Cancer Staging Tool

Significant developments have been made by NICR staff working with the international Association of Cancer Registries to update the cancer staging tool which aims to facilitate increased cancer staging internationally. A standalone version has been developed to enable registries to use the tool without accessing the internet. The initial online version of the tool provided five cancer sites for TNM version 7 staging – breast, cervix, colorectal, lung and prostate. Now the tool provides the capability to stage these cancers also in the new TNM version 8 classification. Furthermore, the staging tool has been expanded to include the following six cancer sites, providing the ability to stage all sites in both TNM 7 and 8 versions:

- Liver
- Melanoma
- Oesophagus
- Ovary
- Pancreas
- Stomach

An example of the TNM version 8 input screen for cervical cancer staging is shown below:

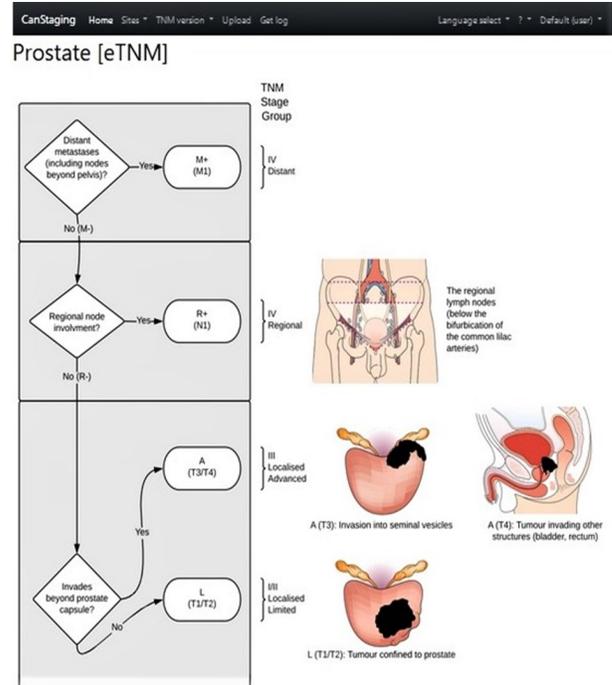
CanStaging Home Sites ▾ TNM version ▾ Upload Get log Language select ▾ ? ▾ anyone (user) ▾

Cervix [v8]

Tumour ID:	0	<input checked="" type="checkbox"/> Auto
T	TX	
Microscopic lesion only	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
Stromal invasion	Please Choose ▾	Reset
Clinically visible lesion	Please Choose ▾	Reset
Tumour invades beyond uterus	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
Parametrial involvement	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
Carcinoma involves lower 1/3 of vagina	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
Extension onto pelvic wall	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
Hydronephrosis or non-functioning kidney	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
Tumour invades mucosa of bladder or rectum	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Don't know	
N	NX	
Number of positive nodes	▾	
M	M0	
Distant metastases	No distant metastases ▾ Reset	
SG		
FIGO		
SimpG		
SG range		
TNM		
TNM with prefixes		

Get log Reset form Submit

The new essential TNM classification continues to be developed and the currently released flow diagrams for breast, cervix, colon/rectum and prostate have been incorporated within the tool. Further cancers will be added as the essential TNM classification expands. See example for prostate cancer:



Images and diagrams have been added to give visual indications of different tumour stages in the various cancer sites. These diagrams have been designed to assist with the determination of the various elements of the TNM stage by displaying a pop up when the user hovers the mouse over a specific input - see example below for staging the T component of colorectal cancer in TNM version 8 based on the level of invasion:

Additional cancer sites are being planned; however, the tool is currently undergoing a period of testing to ensure correct staging values are returned based on user inputs. In time, we are also hoping to expand the language support within the tool – currently it has some support for the French, Spanish and Portuguese languages. It is hoped that by the end of 2020 an online version of the tool will be available.

CENTR³IS - NICR IT Development Project

It became obvious in 2017/18 that there was a requirement to upgrade the existing Cancer Registration application used by NICR and despite extensive research into off the shelf applications and collaborations it was decided that the best option for NICR was to develop a bespoke application based on the existing practices, procedures and information flows available to them. The functional and technical requirements were drawn up and in 2019, NICR employed a developer, Mr Paul Frew, to work along with staff and draw upon their many years of expertise to replicate best working practices and workflows for Cancer Registration Services in Northern Ireland. The system is also designed to be somewhat more future-proof and allow for the adoption of new working practices, coding guidelines and information types available. It is hoped that the new system, named CENTR³IS (Cancer & Epidemiology in Northern Ireland Registration, Reporting and Research Information System) will be ready for a parallel testing by the end of 2020 with a view to full operational roll-out by April 2021.

The logo for CENTR³IS is displayed in a large, bold, blue font. The letters 'CENTR' are in a standard weight, while the '3' is a smaller, superscripted font. The 'IS' is in the same bold weight as 'CENTR'. The entire logo is reflected below it, creating a mirror image effect.

Cancer & Epidemiology in Northern Ireland Tracking Recording, Registration and Reporting Information System.

Audits

National Mesothelioma Audit report 2020 (for the audit period 2016-18) – A First for N Ireland

Data collected by the N Ireland Cancer Registry (NICR) has been included in an audit of mesothelioma cancer. The National Mesothelioma Audit report 2020 (<https://www.rcplondon.ac.uk/projects/outputs/national-mesothelioma-audit-report-2020-audit-period-2016-18>) published in May 2020 is the fourth in a series of publications produced in collaboration with the Royal College of Physicians, Public Health England and Mesothelioma UK. The audit aims to highlight information about this asbestos related cancer. Data were collected on patients diagnosed with mesothelioma from England and Wales, and for the first time, includes N.Ireland and Guernsey. These patients, totalling over seven thousand, were diagnosed between 1 January 2016 and 31 December 2018 and included both malignant pleural mesothelioma (MPM) and peritoneal mesothelioma (PM).

Highlights from the recent report includes: -

- 7,210 patients (6,950 (MPM) & 260 (PM)) diagnosed in 2016-2018 period, up from 7,192 in 2014-2016 period.
- MPM patients included 83% male vs 17% female with an overall median age of 76. Three-year survival for these patients increased to 10% compared to 7% in previous report.
- PM patients included 64% male vs 36% female with an overall median age of 71. Three-year survival for these patients increased to 18% compared to 7% in previous report.
- Data completeness for MPM patients increased over time, with a particular note to increases in Performance Status, Stage at Diagnosis and the completion of patients having been accessed by a Clinical Nurse Specialist (CNS).
- Another welcome improvement occurred with the number of MPM patients being discussed at a Multidisciplinary Team (MDT) meeting, increasing to 89% of patients.
- Numbers of MPM patients receiving Radiotherapy treatments have declined in this recent report, down from 22% in 2018 report to currently 15%.

This audit will have implications locally for future mesothelioma patients and the services provided to them by providing a baseline measurement to benchmark services beyond 2020.

Audits

Colorectal Audit

Northern Ireland has not had a regional audit for incident colorectal cancer and the care of its patients since 2006. The Northern Ireland Cancer Network (NICaN) Colorectal Clinical Reference Group (CRG) requested that the NICR do a regional audit of cancer patients with colorectal cancer similar to peer reports based in England/Wales and Scotland. The Public Health Agency funded the report for patients diagnosed with a colorectal cancer in 2018. The study design is novel as it has been done with a lot of input in terms of data collection from clinicians and clinical nurse specialists alongside input from the multidisciplinary team within the NICR. To date the NICR has received all data from four out of five Health and Social Care Trusts for patients diagnosed during 2018. Data collection from the NICR is now complete and will now be checked analysed by Dr Karen Cafferkey and Dr Jamie Roebuck. This project has been hampered by delays due to high volumes of clinical work-load and the COVID-19 crisis. We are hoping to publish the report later this year.

Oesophagus Audit

The NICR was successful in a grant application for an oesophageal cancer audit for patients diagnosed in 2017 and 2018. The grant has been awarded by the Regulation and Quality Improvement Authority (RQIA) as part of the RQIA Audit, Guidelines and Quality Improvement Programme 2020/2021. The project is due to commence in October 2020 and the scope is to look at Key Performance Indicators surrounding the care of squamous cell oesophageal carcinoma patients and adenocarcinoma patients. This is a regional piece of work and will look at diagnosis, treatment and follow up of the 445 patients in this cohort. Previous regional audits of oesophageal cancer audits took place in 1996, 2001 and 2005.

Audits

National Cancer Diagnosis Audit (NCDA) – Northern Ireland

Why a National Cancer Diagnosis Audit (NCDA)?

- Improving the early diagnosis of cancer and shortening intervals to cancer diagnosis are important focus areas in Northern Ireland (NI).
- There is currently no mechanism for directly assessing progress (or lack of it) in diagnostic timeliness that takes into account the full diagnostic pathway, chiefly because there is no routine mechanism for measuring the primary care interval (the time from first presentation to specialist referral for cancer patients).

What is the NCDA?

- The NCDA is a UK-wide project led by Cancer Research UK, together with various partner organisations, including Public Health England, Public Health Wales, NHS England, NHS Scotland, Macmillan and the Royal College of General Practitioners (RCGP).
- The audit collects data relating to patient pathways to cancer diagnosis from first contact with primary care through to the date of cancer diagnosis. It combines data available in Cancer Registries with data gathered directly from primary care to provide detailed insights into complete patient pathways.

What is the value of the NCDA?

- The NCDA data provides detailed insights into patient pathways to cancer diagnosis through primary care, never previously available at a national level and at this scale, and not available through other routinely collected datasets.

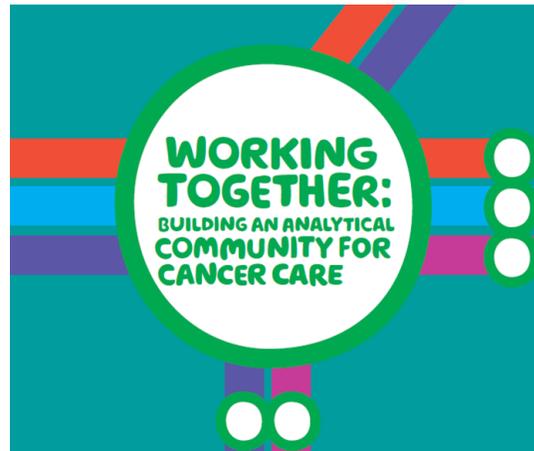
What is happening with the pilot of the NCDA in Northern Ireland?

Cancer Research UK are funding the Northern Ireland Cancer Registry to undertake a pilot NCDA with up to 10 GP practices in Northern Ireland. Despite delays in starting the audit due to the coronavirus pandemic contact has been made with a number of interested GPs and will start in July 2020. Findings from the pilot audit should be available by November 2020 in line with the findings from the rest of the UK. If you are an interested GP practice there is still time to join up, please contact the Registry at nicr@qub.ac.uk.

Conferences

Macmillan- Working together: building an analytical community for cancer care

Registry staff from the NICR-Macmillan partnership attended the first Macmillan analytical community conference in September 2019. This conference was established to bring together analysts across the UK and share their knowledge of analytical approaches. The benefit of collaborative work was highlighted through the countless partnerships between the public sector, universities, and charities. Analysts were given the opportunity to discuss strategies to solve common challenges faced, such as developing effective language and encouraging open clinical engagement. Dr Victoria Cairnduff gave a presentation about the NI Cancer Registry and our ongoing projects with Macmillan. Dr Victoria Cairnduff also participated in a quick-fire session in which she presented her research on “Investigating characteristics of women with Breast Cancer Recurrence in NI”.



NICR Refurbishment

The Queen’s University has agreed a complete refurbishment of the NI Cancer Registry premises to provide a welcoming, secure and collaborative space for the Registry. The excellent Estates department are now nearing the end of the design process. The refurbishment will breathe a new lease of life into the registry with removal of old and outdated offices and narrow corridors to be replaced with open space offices, natural lighting, heating and cooling and updated information technology, communications and security access provisions. Although the design process is at an advanced stage, unfortunately due to the COVID-19 crisis, the decant to temporary accommodation in an alternative part of the building and refurbishment works have been delayed for a period of time. In the meantime most staff continue to work remotely with key staff able to enter the registry when required, working at safe distances, to ensure that the ongoing work of the NICR continues.

NICR Publications June 2019-June 2020

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Predictors of an early death in patients diagnosed with colon cancer: a retrospective case-control study in the United Kingdom. 19 Jun 2019, In : BMJ Open. 9, 6, p. e026057 12 p., e026057. <https://doi.org/10.1136/bmjopen-2018-026057>

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Arnold, M., Rutherford, M. J., Bardot, A., Ferlay, J., Andersson, T. M-L., Myklebust, T. Å., Tervonen, H., Thursfield, V., Ransom, D., Shack, L., Woods, R. R., Turner, D., Leonfellner, S., Ryan, S., Saint-Jacques, N., De, P., McClure, C., Ramanakumar, A. V., Stuart-Panko, H., Engholm, G., **Gavin, A.** & 17 others,

Progress in cancer survival, mortality, and incidence in seven high-income countries 1995-2014 (ICBP SURVMARK-2): a population-based study. 11 Sep 2019, In : Lancet Oncology. [https://doi.org/10.1016/S1470-2045\(19\)30456-5](https://doi.org/10.1016/S1470-2045(19)30456-5)

Wilding, S., Downing, A., Wright, P., Selby, P. J., Watson, E., Wagland, R., **Donnelly, D.**, Hounsome, L., Butcher, H., Mason, M., Henry, A., **Gavin, A.** & Glaser, A. W.

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Gavin, A., Verhoeven, D., Kaufman, C. S., Mansel, R. & Siesling, S.
Breast cancer: Global quality care. 19 Nov 2019, Oxford University press.

Menon, U., Vedsted, P., Zalounina Falborg, A., Jensen, H., Harrison, S., Reguilon, I., Barisic, A., Bergin, R. J., Brewster, D. H., Butler, J., Brustugun, O. T., Bucher, O., Cairnduff, V., **Gavin, A.**, Grunfeld, E., Harland, E., Kalsi, J., Knudsen, A. K., Lambe, M., Law, R-J. & 6 others.
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Staff News

New Staff

In September 2019 we welcomed Dr Tewodros Getachew to the Registry. Tewodros is the NICR's new Statistician, replacing Dr Eileen Morgan.

In December 2019 we welcomed both Ms Helen Mitchell and Dr Karen Cafferkey. Helen replaced Dr Victoria Cairnduff as Statistician on the Macmillan project. Karen joins the Registry as Statistician for Datacan, a new research project. She will be working on analysis of the Colorectal audit and will also be working on the Oesophageal audit.

We hope all new members of staff settle well into their new roles.



(L-R Ms Helen Mitchell, Dr Karen Cafferkey, Dr Tewodros Getachew)

Farewell



The Registry said goodbye to one of our TVOs, Jacqui Napier in November 2019. Jacqui returned home to Newcastle-upon-Tyne and we send her every best wish as she settles in back home - she will be greatly missed!



We also say goodbye to our Deputy Director, Prof Lesley Anderson. After 20+ years Lesley leaves Queen's University to take up a professorial post within Aberdeen University. We would like to thank Lesley for her help and support over the past number of years in the Registry and we wish her and her family every success in their move to Scotland.

Staff News

Congratulations!

The Registry would like to congratulate one of our TVOs, Laura Simpson, on her recent marriage. We wish you and Barry many years of happiness!

Thank you!

The Registry would like to thank both Heather Monteverde of Macmillan, and Roisin Foster of Cancer Focus for all their help and support on the NICR Council and Steering Group, respectively, over the past number of years. Both Heather and Roisin leave their respective posts at the end of Summer 2020 and we wish them every happiness in their futures.

(Top: Ms Heather Monteverde; Bottom: Ms Roisin Foster)



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