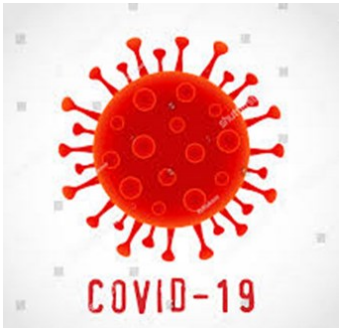
Northern Ireland Cancer Registry

July 2021
Volume 27

NICR Newsletter

Response to the COVID-19 Crisis

Since April 2020 the Registry has produced Covid Impact analysis on Cancer Pathology data. See pages 2-3 for more detail.



Thanks to the work of the Registry IT department and Data Manager secure remote access to Registry systems are in place with appropriate agreements from the relevant Health and Social Care Trusts. This has enabled Registry Staff to continue to work from home as normal.

Official Statistics Launch 2021

Official Statistics on cancers diagnosed in Northern Ireland during 1993-2019 will be published in September 2021, with an exact release date to be announced in July. This release will provide 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. Newly added this year will be information on incidence trends by age group, incidence and survival by method of most recent inpatient admission to hospital (e.g. emergency admissions) and incidence and survival for those patients detected by a screening programme. The information will be available as summary factsheets, along with spreadsheets containing detailed tabular data and will be released via the NICR website.

NICR Refurbishment

Due to ongoing plans to relocate Research Centre's closer to the main QUB site the full refurbishment of the NICR offices will take the form of an uplift. This work is currently ongoing with the hope to be completed in the Autumn.

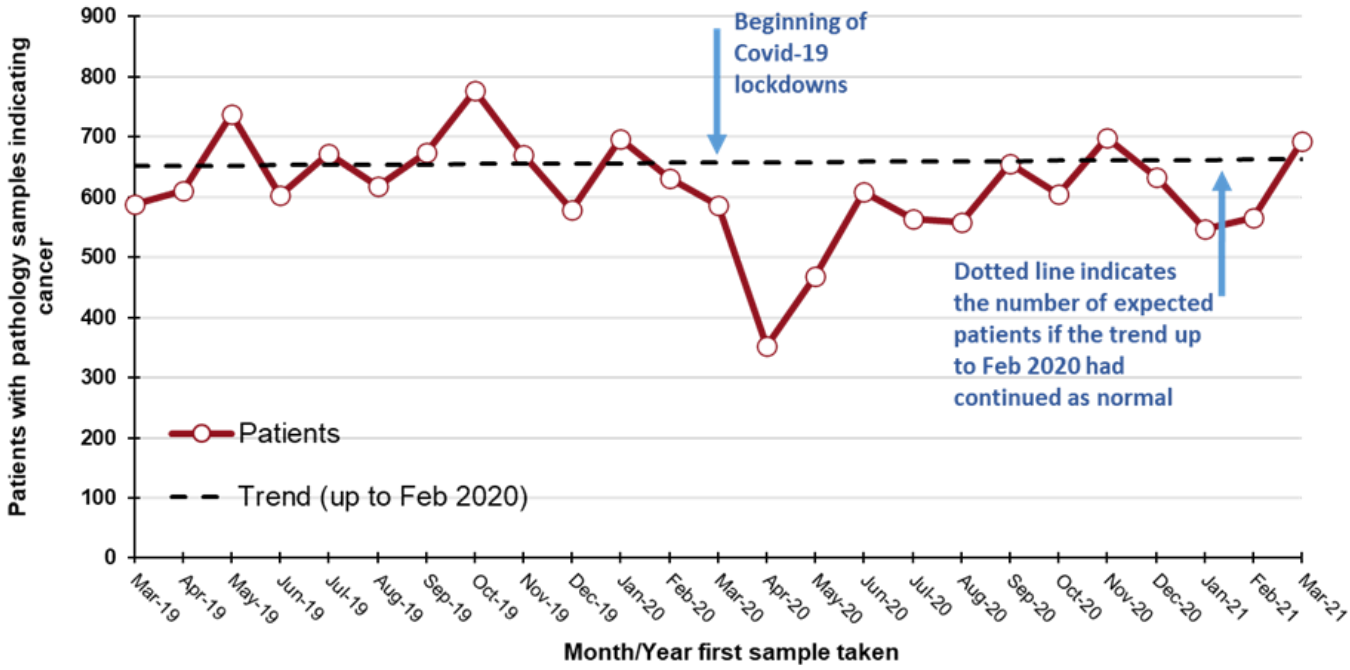
Inside this issue

The impact of the COVID-19 pandemic on diagnosis

Since the second half of March 2020 lockdown restrictions of varying degree have been in place in Northern Ireland to help prevent the spread of the COVID-19 virus. Consequently some key cancer services 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 the Covid-19 pandemic on cancer diagnosis, the NI Cancer Registry (NICR) has been producing a monthly overview of recent trends in the number of patients with pathology samples indicating cancer, with these trends contrasted with similar data from 2017-2019.

In the 13 months from the start of March 2020 to the end of March 2021 the number of patients with a pathological sample indicating cancer was 10% lower than the average number for the same time period in 2017-2019, equivalent to approximately 1,000 fewer patients. Many of these patients may have been diagnosed clinically (e.g. via X-rays or CT scans), but are consequently more likely to have been diagnosed at a later stage or at an emergency hospital admission. The downturn in patient numbers was at its worst in April and May of 2020, with levels steadily improving up to November 2020, however, a drop-off occurred again in January 2021 as a result of tighter Covid-19 restrictions. Fortunately, signs of recovery were already evident by March 2021 with patient numbers slightly above expected levels.

Figure 1: Trend in patients with pathology samples indicating cancer by month and year first sample taken

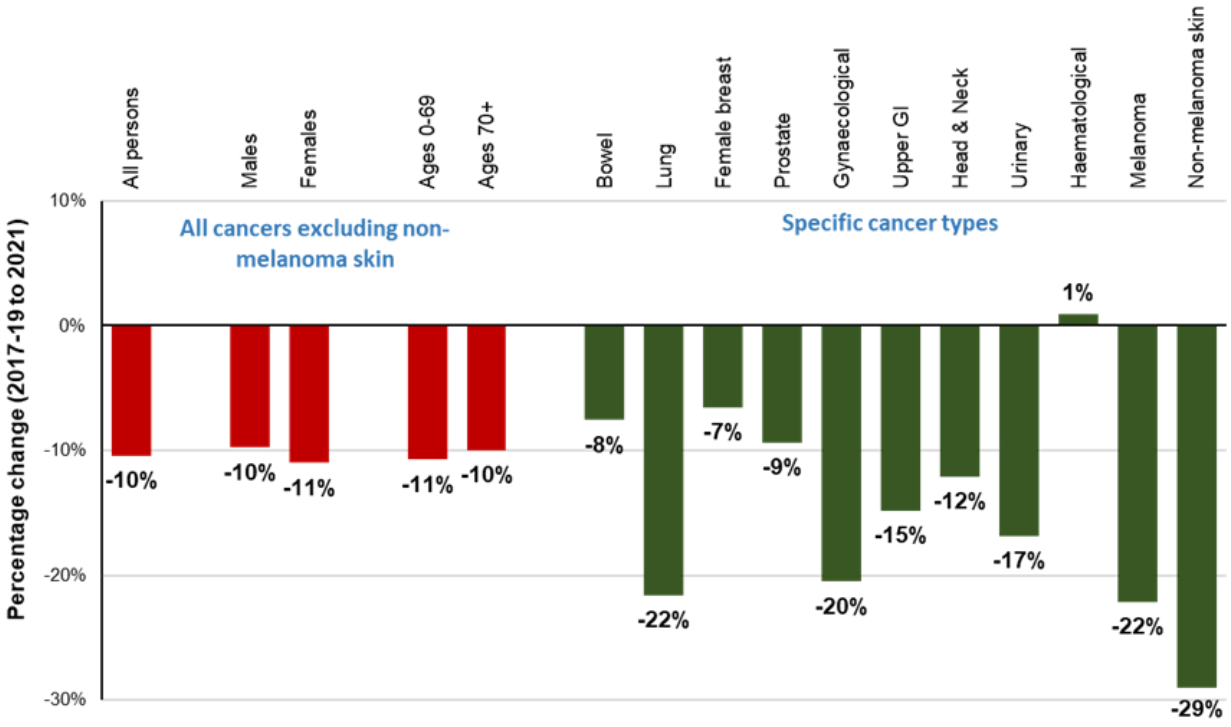


Note: Data were sourced from the four NHS pathology laboratories in Northern Ireland (Belfast, Altnagelvin, Antrim, Craigavon), which are usually provided to the NICR on a monthly basis. However, only cytology from Altnagelvin is included in this summary due to a change over to a new recording system resulting in histology data from Altnagelvin temporarily being unavailable.

While the impact on cancer patient volume resulting from the pandemic was similar for men and women and for those over and under age 70, the impact and recovery was not the same for all types of cancer. Among the different cancer types only the number of patients diagnosed pathologically with haematological cancers appears to be at the expected level for the 13 months up to the end of March 2021. However, lung cancer, gynaecological cancer and both types of skin cancer (melanoma and non melanoma skin cancer) were one fifth or more below the expected level. This is particularly troubling for lung cancer which is a poor survival cancer for which early diagnosis is critical. Some of the more common cancer types (breast, bowel and prostate cancers) had decreases in patient volumes of between 5 and 10%, while upper gastrointestinal cancers, urinary cancers and head and neck cancers all had decreases of between 10 and 20%.

NICR will continue to monitor the impact of the Covid-19 pandemic on cancer services for as long as required by service providers. Updates are produced by the end of each month, and made publicly available on the NICR web site (https://www.qub.ac.uk/research-centres/nicr/Publications/ImpactofCOVID-19onCancerDiagnosis).

Figure 2: Percentage change from 2017-2019 to 2020/2021 in the number of patients with pathology samples indicating cancer

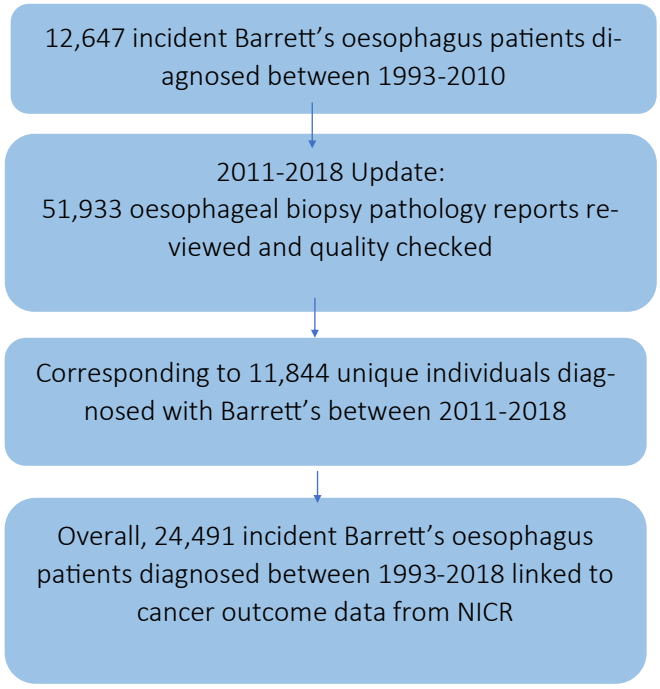


Research Highlights

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 50,000 pathology reports from 2011-2018 have now been reviewed.

In February 2021, the NIBR team said farewell to Mr Andrew Hamilton and welcomed Mr Sean Morrison back from his secondment with the QUB Student Guidance Centre. We thank Andrew for his invaluable contribution to the NIBR update and wish him every success in his new role with the endometrial hyperplasia register.
The update of the register including over 24,000 patients diagnosed with Barrett's oesophagus between 1993 and 2018 has recently been linked to the NICR dataset for cancer outcomes.

Northern Ireland's Barrett's Register



Research Highlights

The analysis planned for this work will allow Professor Helen Coleman, Dr Victoria Cairnduff and the wider study team to investigate trends in diagnoses of Barrett's oesophagus, and progression to dysplasia and oesophageal adenocarcinoma, now that new endoscopic treatments such as Endoscopic Mucosal Resection (EMR) and Radiofrequency ablation (RFA) are available.

Sean Morrison

Dr Talita Oliveira

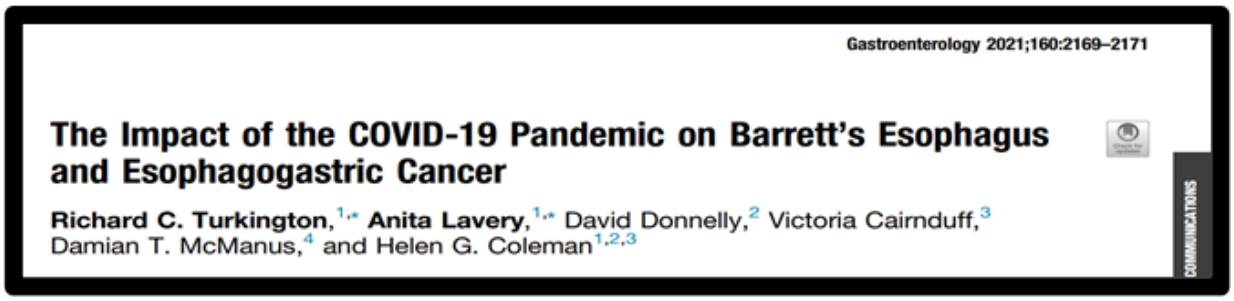
Dr Victoria Cairnduff

Dr Talita Oliveira joined the NI Barrett's team in October 2020 to commence work on a one-year Cancer Research UK funded 'Primer Award' to investigate a biomarker for assessing the molecular age of Barrett's tissue. It is hoped that this work will help with estimating how long someone might have had Barrett's oesophagus before their diagnosis. This work is being led by Professor Helen Coleman in collaboration with the NIBR team, Dr Kit Curtius at the University of California San Diego, Dr AJ McKnight (CPH) with the NIBR database used as a sampling frame for this project.

Barrett's oesophagus was a main theme at the 3rd Annual Professor Liam Murray Symposium held on 27th January 2021 with the Northern Ireland Barrett's oesophagus Research Public and Patient Involvement (PPI) group providing an insight into the challenges that a diagnosis of Barrett's oesophagus represents for patients. Professor Rebecca Fitzgerald (keynote speaker) presented her groundbreaking work on the design and implementation of the Cytosponge into routine clinical practice. The NIBR update and biomarker work were presented as posters during the symposium.

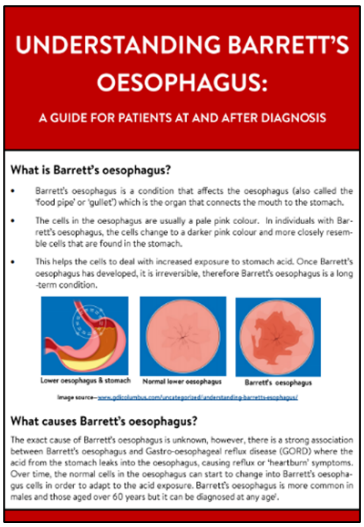
Prof Rebecca Fitzgerald

Research Highlights



The NIBR team were involved in preparing a Brief Communication on the impact of the COVID-19 pandemic on Barrett's oesophagus and oesophago-gastric cancer published in Gastroenterology in May 2021.

The findings showed that between March and September 2020, there were 53 fewer oesophago-gastric cancer diagnoses than expected compared to March to September 2017-2019, a decrease of 26.6%.There were also 236 fewer Barrett's oesophagus diagnoses than expected compared to the same time period 2017-2019, a decrease of 59.3%.


UNDERSTANDING BARRETT'S OESOPHAGUS:

A GUIDE FOR PATIENTS AT AND AFTER DIAGNOSIS

What is Barrett's oesophagus?

- Barrett's oesophagus is a condition that affects the oesophagus (also called the 'food pipe' or 'gullet') which is the organ that connects the mouth to the stomach.
- The cells in the oesophagus are usually a pale pink colour. In individuals with Barrett's oesophagus, the cells change to a darker pink colour and more closely resemble cells that are found in the stomach.
- This helps the cells to deal with increased exposure to stomach acid. Once Barrett's oesophagus has developed, it is irreversible, therefore Barrett's oesophagus is a long-term condition.

Lower oesophagus & stomach | Normal lower oesophagus | Barrett's oesophagus

Image source– www.gicolumbus.com/uncategorised/understanding-barretts-oesophagus/

What causes Barrett's oesophagus?

The exact cause of Barrett's oesophagus is unknown, however, there is a strong association between Barrett's oesophagus and Gastro-oesophageal reflux disease (GORD) where the acid from the stomach leaks into the oesophagus, causing reflux or 'heartburn' symptoms. Over time, the normal cells in the oesophagus can start to change into Barrett's oesophagus cells in order to adapt to the acid exposure. Barrett's oesophagus is more common in males and those aged over 60 years but it can be diagnosed at any age[1].

In other news, the NIBR research team have been working in collaboration with the Northern Ireland Barrett's oesophagus Research Public and Patient Involvement (PPI) group to co-produce an information resource for Barrett's oesophagus patients following their diagnosis.

The leaflet, which has received very positive feedback is in the final stages of production and the next stage will involve implementation into use in Gastroenterology clinics across Northern Ireland. We are very grateful to our PPI group members: Rhonda Campbell, John Clarke, Mark Kelly and Rosemary McAnerney, for identifying this previously unmet need for Barrett's oesophagus patients in NI.

Research Highlights

Northern Ireland Endometrial Hyperplasia Register

Dr Úna McMenamin from the Centre for Public Health was awarded a UK Research and Innovation Future Leaders Fellowship in 2020 to conduct research into endometrial cancer, also referred to as womb cancer, and its precursor condition, endometrial hyperplasia.

Dr Úna McMenamin

Why conduct research in this area?

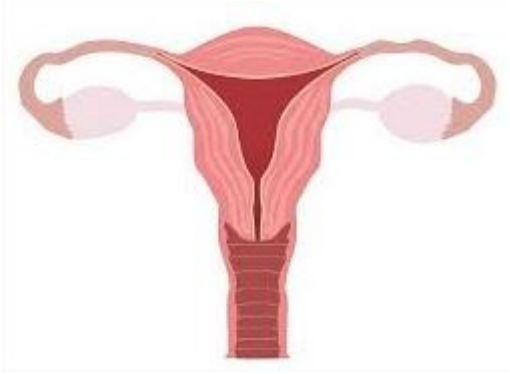
Endometrial cancer is the most commonly diagnosed gynaecological cancer and is the 4th most common cancer among women in Northern Ireland.

The incidence of endometrial cancer is rapidly rising in incidence, including in younger women, and there is currently no routine screening for this cancer.

Primary treatment involves a hysterectomy, meaning a woman is forced to lose her fertility if treatment is required.

Endometrial hyperplasia is a recognised precursor, which if detected, can help to prevent the disease progressing to endometrial cancer.

What will we do as part of this project?



As part of this new project, Dr McMenamin will develop the Northern Ireland Endometrial Hyperplasia Register within the Northern Ireland Cancer Registry (NICR), which will be the first of its kind in the UK. The Register will consist of incident endometrial hyperplasia cases diagnosed from 2008-2020, identified from endometrial biopsy pathology reports and building on pilot work led by Prof Helen Coleman. The Register will be securely linked to NICR records to determine temporal trends in endometrial hyperplasia incidence and progression to endometrial cancer. Additional novel secure data linkages to drug dispensing and maternity records in Northern Ireland will be conducted to evaluate population patterns of non-surgical hormonal therapies in endometrial hyperplasia patients and their long-term impact on clinical outcomes such as hysterectomy, live births and progression to cancer.

What progress has been made so far?

In February 2021, Mr Andrew Hamilton joined the team to review endometrial pathology reports.

A Postdoctoral Researcher will be recruited in the coming months.

A PhD student will join the team in September 2021.

The project involves input from clinicians in the Belfast and Northern Trust.

An endometrial hyperplasia patient involvement group is currently being established to provide essential patient perspectives to the project.

Research Highlights

The Descriptive Epidemiology of Male Breast Cancer in Northern Ireland between 1993-2018

Emma Whiteside

The NICR team was proud to support undergraduate BSc Human Biology student, Emma Whiteside, for her final year dissertation, which focused on the epidemiology of male breast cancer in Northern Ireland. Emma was supervised by Prof Anna Gavin, Dr Nick Orr and Prof Helen Coleman. Emma's findings showed that although male breast cancer is rare overall, the incidence in older men is higher than previously thought. Emma has submitted an abstract based on her findings to the ENCR conference later in 2021 (see below).

Emma hopes to go on to do Physician Associate studies, and we wish her every success for her future career.

Background

Male breast cancer (MBC) is considered a rare disease, but little is known about its epidemiology in the UK. A paucity of MBC research has led to treatments typically being extrapolated from female breast cancer. We performed epidemiological analysis of MBC in Northern Ireland (NI) between 1993 and 2018, to help inform public health initiatives and health service planning.

Methods

Anonymised Data on 204 MBC cases were provided by the NICR. Patient demographics, tumour characteristics, treatment and survival were summarised using descriptive statistics. Association analyses used chi-squared tests, t-tests, and Cox regression tests to explore relationships between variables. Male data were compared to female data taken from a 2012 NICR audit.

Results

Over the last 25 years MBC incidence in NI has remained stable, with a mean annual incidence of 1.23 cases per 100,000 males. Average annual MBC incidence was highest in men aged 75 years and older (10.16 per 100,000 males), different from female breast cancer (FBC), where incidence was highest in 50–64-year-olds. Cases aged 70+ years were often diagnosed with a later stage cancer (P=0.04). Surgery was the most common treatment method. Observed 5-year survival was 65.7% for males compared to 77.4% for females. Survival was poorer with later stage diagnosis (P<0.001)-.

Conclusions

The average annual incidence rate of MBC in NI was 1.23 per 100,000 males, meeting the definition of a rare cancer (defined as <6 per 100,000 males). However, the MBC incidence in men aged over 75 years exceeds this threshold (10.16 per 100,000 males). Poorer observed survival relative to female breast cancer may be related to late presentation, highlighting a need for increased awareness of MBC, particularly in older men.

Research Highlights

International Covid Comparisons - MSc Student Jennifer McClean

The dissertation of Global Health Master's student Jennifer McClean, who is supervised by Prof Anna Gavin, aims to explore how national country policies during the time of COVID-19 have affected cancer cases in N. Ireland, the Netherlands and New Zealand exploring data on breast, lung and colorectal cancers. Breast and colorectal cancer both have screening services that were halted during COVID-19 lockdown measures in many countries which may affect the number of cases picked up while lung cancer cases may have been missed if symptoms were mistakenly attributed to COVID-19. Published data are being analysed including that from the monthly pathology reports prepared by Dr David Donnelly of the NICR while Dr Otto Visser, Netherlands and Dr Elinor Millar New Zealand have been very generous with their time providing information from their home nations.

What impact has COVID-19 had for oral cancer diagnosis in Northern Ireland?

Dr Peter Morrison

Dr Peter Morrison is a Master of Public Health student at QUB, supervised by Dr Gerry McKenna, School of Dentistry, currently using anonymised data from the NICR to examine trends relating to oral cancer diagnosis in Northern Ireland. The comprehensive dataset from as early as 1993, when Peter was born, allows for a range of variables such as tumour stage at diagnosis and deprivation status to be examined. While the impact of COVID-19 on these trends is not yet fully known at this stage, early reports from local pathology laboratories demonstrate the unfortunate reality of cases that have not been caught over the past year.

Research Highlights

Investigating the impact of COVID-19 on routes to hospital admission for cancer patients from March – December 2020 in Northern Ireland with comparisons to a pre-COVID era.

Ben Alford

Ben Alford, a MSc student, has been working with Helen Mitchell, NICR Statistician and Prof Anna Gavin, investigating the impact COVID-19 has had on NI cancer services as a result of the nationwide lockdown put in place in late March 2020 using anonymised Public Administration System (PAS) data from 1st March to 31st December 2020 and comparing this to similar data from 2017 – 2019. PAS data gives access to patient demographics, such as age and sex, and cancer type (using ICD codes), which enables assessment if a certain demographic or cancer has been more heavily impacted by the lockdown.

Furthermore, the work will compare patients by socioeconomic status, proximity to hospital, which Health and Social Care trust they are a part of, and whether they reside in a rural or urban area to investigate which societal groups have been most severely impacted by the disruption of NI cancer services due to COVID-19. There will be focus on patients who have presented as an emergency case to hospital (e.g., admission via A&E or ambulance services) and have a cancer diagnosis as their primary diagnosis, or secondary diagnosis if it is related to their primary diagnosis (e.g., 1° = K56 bowel obstruction / 2° = C18 – C20 bowel cancer). Basic comparisons will be made using percentages and frequencies with further analysis via a logistic regression model. Additionally, sensitivity analysis will be undertaken to test the robustness of our findings.

Thanks to Eamon O'Callaghan, NICR, who has worked to receive the PAS Data to the Registry.

Research Highlights

NI Premalignant Cervical Lesions Register (NIPCLR)

Thanks to generous donations received from the Lynsey Courtney Foundation, work began in May 2020 on the Northern Ireland Premalignant Cervical Lesions Register (NIPCLR).

The most common types of cervical cancer are known to develop from abnormal changes in the cells lining the cervix, which can often be detected at an early precancerous (premalignant) stage. These abnormal changes are usually triggered following infection with certain subtypes of human papilloma virus (HPV).

The aim of the register is to develop an accurate and complete database of all high-risk precancerous changes in the cervix affecting women in Northern Ireland, and to collect data relating to their diagnosis, HPV status and aspects of their treatment. This resource will be used to:

- monitor the number of cases of cervical premalignant lesions over time
- improve our understanding of how abnormal cervical changes progress
- investigate the effectiveness of current treatments
- evaluate the impact of the cervical smear screening and HPV vaccination programmes
- assess the effect of the COVID-19 pandemic on the provision of these services.

Work to date has been undertaken by NICR Tumour Verification Officer, Dr Jamie Roebuck, and is currently at an early stage and has focused on piloting different formats for the dataset, establishing the data fields to collect, and liaising with potential end users of the data to ensure its accessibility and usefulness.

So far, data collection for precancerous changes diagnosed in 2018 or 2019 is almost complete, with nearly 2,000 patients in the database and analysis of over 10,000 pathology reports. Anonymised Data from the register are already being used by a PhD student in the Centre for Public Health at Queen's University Belfast, Sarah Alawi.

We are extremely grateful to the Lynsey Courtney Foundation who have provided the funding to allow this work to take place.

Dr Jamie Roebuck

Research Highlights

Heart Health and Cancer

This research is a cross disciplinary project involving the cardiologists Dr Mark Harbinson and Dr Gerard Walls with Prof Ciaran O'Neill, Deputy Director, NICR and Dr David Donnelly, examining the impact of heart disease before cancer on outcomes and how cancer treatments affect cancer.
While cancer outcomes have improved over time, in N. Ireland they continue to lag behind those of many other developed economies. The role of co-morbid conditions has been suggested as a potential contributory factor for poorer outcomes though issues with the comparability of data across jurisdictions has inhibited efforts to explore these relationships. We use data from a single jurisdiction - the N. Ireland Cancer Registry – where consistent coding operates, to examine the association between mortality (all-cause and cancer specific) and pre-existing heart disease among patients with cancer.

The methods used are that all patients diagnosed with cancer (excluding non-melanoma skin cancer) between 2011 and 2014 were identified from Registry records. Those with a pre-existing diagnosis of heart disease were identified by record linkage using ICD10 codes. Survival in the five years following diagnosis was examined using descriptive statistics and Cox proportional hazards regression analyses. Analyses examined all-cause mortality and cancer specific mortality for lung, colorectal, breast and prostate cancer. As well as heart disease, regression models controlled for a range of covariates including sex, age, stage at diagnosis, deprivation and co-morbidity indices.

We found that almost 35,000 incident cases of cancer were diagnosed during the study period of which approximately 23% had a prior heart condition. The pan-cancer hazard ratio for death in the presence of pre-existing heart disease was 1.28 (95% CI 1.18-1.40). All-cause and cancer specific mortality was significantly higher for patients with heart disease across lung, female breast and groups after controlling for the various covariates.

This means that pre-existing morbidity compromises patient resilience to cancer and limit the range of available treatments. In this Northern Irish cohort, patients with cancer and pre-existing heart disease had poorer outcomes than those without heart disease. A high prevalence of heart disease may contribute to poorer cancer outcomes at a national level. Further analysis is being organised.

Research Highlights

NICR-Macmillan Partnership 2019-2020

The NICR-Macmillan partnership is now in its sixth 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 the factors associated with emergency admissions in the last year of life and breast cancer recurrence.

The COVID-19 pandemic led to a pause in the partnership working however this has now resumed. In the next phase of the partnership, projects will include;

- Prevalence cancer in Northern Ireland,
- Recurrences
- The impacts of COVID-19 on cancer patients
- Bone health and cancer

The Cancer Landscape document will be updated to reflect the new Cancer Strategy when it is published later this year. The registry also welcomes Simon O'Hare as the new analyst for the NICR-Macmillan partnership, who took up the post in June.

Biobank/NICR Partnership

The Northern Ireland Biobank (NIB) was established in 2011 to facilitate translational biomarker research, primarily in Northern Ireland but also further afield. The repository is based in the Patrick G Johnston Centre for Cancer Research, Queen's University Belfast. The NIB is an NHS Research Ethics Committee approved Research Tissue Bank which offers benefits in terms of facilitating programmes of research without the need for individual project-based ethical approval.

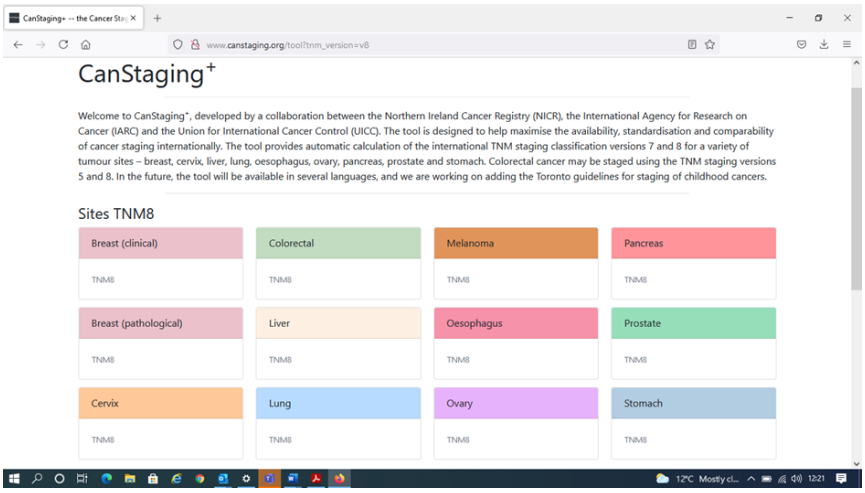
NIB has two core 'collection' strategies. The first is a prospective collection of human samples (tissues, matched bloods and bodily fluids) which initially focused on malignancies and premalignant lesions of the gastrointestinal tract, genitourinary tract, gynaecological tract, lung and breast. Patients are asked to provide broad informed consent for the use of their samples and pseudo-anonymised data to be used for research purposes. Increasingly, the prospective collections are hypothesis led to support specific study requests from researchers.

The second collection is referred to as the NIB 'retrospective' collection. This collection avails of regulated access to samples held in Health and Social Care Trust laboratories for hypothesis led, ethically approved projects. NIB has been instrumental in creating an infrastructure to access and retrieve defined cohorts of formalin-fixed paraffin-embedded material from diagnostic archives and make them available for research use.
The NICR supports the NIB's work by linking anonymised clinical and pathological information stored on the NICR database and that retrieved from HSCNI clinical information systems with pathological samples requested for NIB ethically approved studies. In the NICR, 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 pathology number, no personal identifiers are ever released for NIB studies.

During 2020, the Data Manager and Tumour Verification Officer team has provided data on over 700 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, colorectal and lung cancer. In addition, molecular information on specific gene mutations such as BRAF, NRAS and CKIT was requested. This reflects the increasing importance in identifying those specific genetic mutations that drive each individual patient's cancer in order to provide personalised and targeted treatment. The NICR has recently expanded the Praxis database to collect more molecular information such as HER, ER and PR status which will facilitate the linkage of molecular abnormalities with specific patient pathways, treatment and outcomes by researchers.

CanStaging+ Cancer Staging Tool

The NICR has worked in collaboration with the international Association for Research in Cancer (IARC) to update the cancer staging tool first developed by the NICR. This work is also part of the International Cancer Benchmarking Partnership (ICBP). It aims to facilitate increased cancer staging internationally. The tool can be accessed on http://www.canstaging.org/tool. 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. The new and improved CanStaging now has Essential TNM, TNM7, TNM8 and Toronto Staging Guidelines for Childhood cancers and the number of sites has been expanded to include many more sites as shown in the image below:
A paper has been accepted by the Lancet Oncology Peer Review Team and will soon be published by the journal titled: CanStaging+: an electronic staging tool for population-based cancer registries: Isabelle Soerjomataram; Morten Ervik; Colin Fox; Sinead Hawkins; Kenneth Yeung; Giulio Napolitano; Zuzanna Tittenbrun; Freddie Bray; Anna Gavin



The ongoing work of the CanStaging Group includes
-The expansion of tumour sites included on the tool to include bladder, kidney, endometrium, cervical nodes of unknown primary, oropharynx and larynx.
-The inclusion of the Ann Arbour staging system for lymphoma
-The inclusion of the Toronto Childhood Staging Guidelines which have been endorsed by the European Network of Cancer Registries through working in partnership with The Cancer Council Queensland.
-To have the staging tool available in multiple languages.
-To provide learning and teaching materials for the staging tool users.

Abigail Jeyaraj

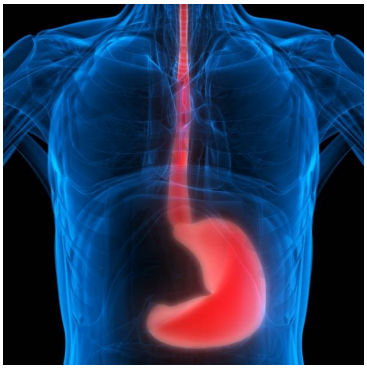
The NICR is happy to announce that Abigail Jeyaraj has been selected to do a studentship with the NICR to help expand the tumour sites and inclusion of the Ann Arbour system.

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. This is particularly timely given the introduction of Bowel Cancer Screening in NI in 2010. The Public Health Agency funded the report, which includes information on 1,097 patients diagnosed with a colorectal cancer in NI in 2018, and a further 19 patients who were diagnosed with synchronous colorectal tumours. The audit has been successfully completed in terms of data collection thanks to efforts from a wide range of clinicians and clinical nurse specialists, alongside input from the multidisciplinary team within the NICR. This audit focuses on Key Performance Indicators benchmarking NI, where possible, with counterparts Scotland, England and Wales with regards to referrals, diagnosis, treatments and survival outcomes. The analysis of this report is in its final stages and has been a huge team effort including Dr Jamie Roebuck, Sinéad Hawkins, Professor Helen Coleman, Dr Karen Cafferkey and Prof Anna Gavin, with thanks also to the wider IT and Data teams in the NICR. The full report will soon be on the NICR website www.qub.ac.uk/nicr

Oesophagus and Stomach Audit



The NICR has received funding from – Regulations and Quality Improvement Agency (RQIA) to undertake an audit on squamous cell carcinoma and adenocarcinoma of Oesophagus. The NICR has are also grateful for funding from local charity OGCancerNI to extend the audit report to include gastric cancers. The report will cover 759 patients diagnosed between 2018 and 2019 and will allow comparisons with the previous pancreatic cancer audit completed by the NICR 2005. Since then there have been large changes in treatment pathways to include centralisation of surgical services. This audit will be analysed in a similar way to the National Oesophago-Gastric Audit and will therefore provide the opportunity for NI care to be compared with that of England and Wales. This audit will also provide key data on OG cancer services pre-covid 19. The report is due October 2021.

The Regulation and Quality Improvement Authority

OGCancerNI
Stomach and Oesophageal Cancer Support

Audits

National Cancer Diagnosis Audit (NCDA) – Northern Ireland

The National Cancer Diagnosis Audit (NCDA) is an in-depth review, conducted by GP practices, of the referral pathway to cancer diagnosis. It collects data from primary care on a range of factors such as referral types used for patients later diagnosed with cancer, use of tests and investigations prior to referral and interval length from patient presentation and referral to diagnosis. The NCDA aims to improve understanding of the pathways to cancer diagnosis and thereby achieve better outcomes for patients. The audit is conducted in England, Wales and Scotland by Cancer Research UK in cooperation with local cancer registries (National Cancer Diagnosis Audit | Cancer Research UK). A pilot study involving six GP practices was conducted in Northern Ireland throughout 2020 by NICR with support from CRUK. Reports on the collected data were provided to the practices who participated, thereby providing tailored feedback to support learning and quality improvement at practice level.

In total 164 completed audits were received. Of these, 19% (n=31) were breast cancer patients, 9% (n=14) were colorectal cancer patients, 15% (n=25) were lung cancer patients and 15% (n=25) were prostate cancer patients. Some key findings included:

- The most common place where the patient first presented with symptoms was the GP Surgery for 61.6% of patients in the NI pilot data, while 7.9% of patients first presented at Accident and Emergency with symptoms related to the cancer diagnosis.
- 61.6% of patients in the pilot had fewer than 3 consultations before referral. The most common reason for multiple consultations was 'Complexity of presentation' (49.4% of reasons given).
- 55.5% of patients in the pilot had at least one primary care led investigation prior to referral. The most commonly used investigation type was a blood test (57.3% of types used).
- The most common route of referral for patients in the pilot was Red-Flag referral for urgent suspected cancer (45.1% of patients). 22.0% of patients in the pilot had an emergency referral.
- The median time from first presentation of symptoms to referral was 9 days, while the median time from first presentation of symptoms to diagnosis was 54 days.

Thanks to Eamon O'Callaghan, Dr David Donnelly, Colin Fox and the CRUK team for their hard work, and funding from CRUK which made this project possible.

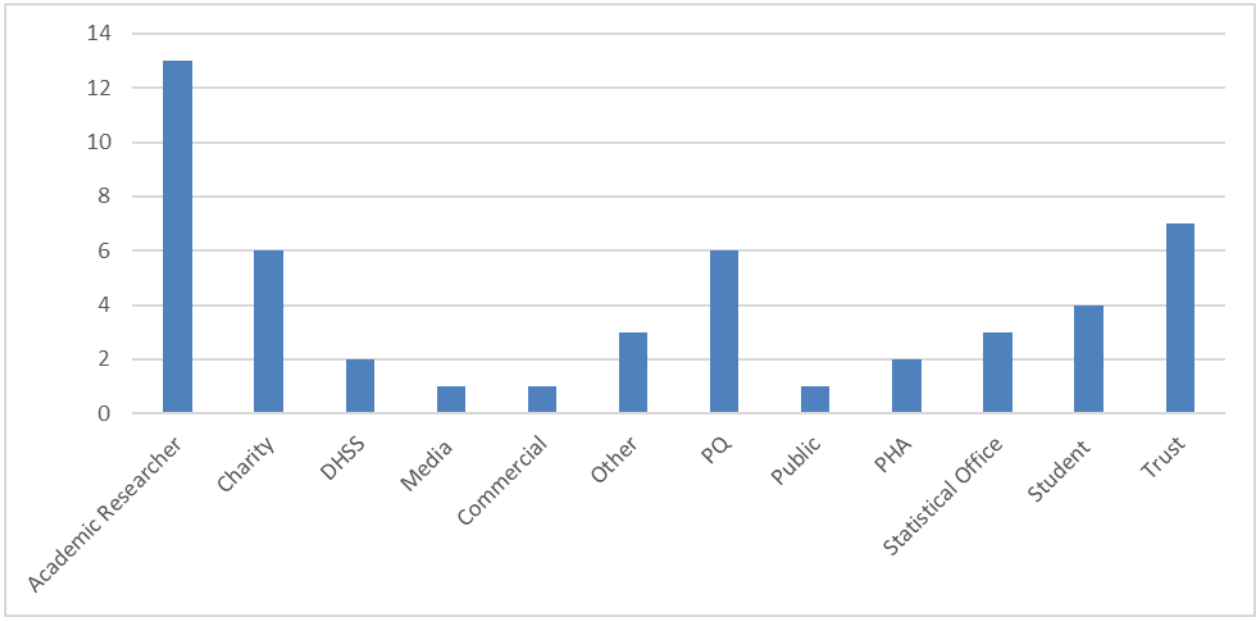
The Registry's Year in Numbers

The NICR provided data and information for 133 requests in 2020, 49 (37%) general requests and 84 (63%) genetic requests (excluding local genetic requests). A nurse from the Medical Genetics department deals with local genetic requests.

In 2020, despite COVID-19 disruption, 98% of general requests for information were completed within the recommended 20 working days and 100% of genetic requests for information were completed within the recommended 10 working days. Figure 1 below shows the source of general requests.

On average general requests took 218 minutes to complete but ranged from 10 minutes to 3360 minutes (56 hours). Genetic requests took 33 minutes to complete however ranged from 10 minutes to 120 minutes.

Figure 1; Source of Requests



Key;
DHSS - Department of Health and Social Services
PHA - Public Health Agency
PQ - Parliamentary Questions

NICR Publications June 2020-June 2021

Kunzmann AT, Coleman HG, Johnston BT, Turkington RC, McManus D, Anderson LA, Thrift AP.
Does Risk of Progression from Barrett's Esophagus to Esophageal Adenocarcinoma Change Based on the Number of Non-dysplastic Endoscopies?
20 July 2021. In: Dig Dis Sci. https://doi.org/10.1007/s10620-020-06483-0

Collaço, N., Wagland, R., Alexis, O., Gavin, A., Glaser, A. & Watson, E. K.
Using the Framework Method for the Analysis of Qualitative Dyadic Data in Health Research
13 May 2021. In: Qualitative Health Research. https://doi.org/10.1177/10497323211011599

Slade, A. L., Retzer, A., Ahmed, K., Kyte, D., Keeley, T., Armes, J., Brown, J. M., Calman, L., Gavin, A., Glaser, A. W., Greenfield, D. M., Lanceley, A., Taylor, R. M., Velikova, G., Turner, G. & Calvert, M. J.
Systematic review of the use of translated patient-reported outcome measures in cancer trials
26 Apr 2021. In: Trials. https://doi.org/10.1186/s13063-021-05255-z

Watson, E., Wilding, S., Matheson, L., Brett, J., McCaughan, E., Downing, A., Wright, P., Cross, W., Selby, P., Butcher, H., Glaser, A., Gavin, A. & Wagland, R.
Experiences of Support for Sexual Dysfunction in Men With Prostate Cancer: Findings From a U.K.-Wide Mixed Methods Study. 26 Feb 2021. In: The journal of sexual medicine. https://doi.org/10.1016/j.jsxm.2020.12.017

Turkington RC, Lavery A, Donnelly D, Cairnduff V, McManus DT, Coleman HG.
The Impact of the COVID-19 Pandemic on Barrett's Esophagus and Esophagogastric Cancer.
26 Jan 2021. In: Gastroenterology. https://doi: 10.1053/j.gastro.2021.01.208 .

Andersson, T. M-L., Myklebust, T. Å., Rutherford, M. J., Møller, B., Soerjomataram, I., Arnold, M., Bray, F., Parkin, D. M., Sasieni, P., Bucher, O., De, P., Engholm, G., Gavin, A., Little, A., Porter, G., Ramanakumar, A. V., Saint-Jacques, N., Walsh, P. M., Woods, R. R. & Lambert, P. C.
The impact of excluding or including Death Certificate Initiated (DCI) cases on estimated cancer survival: A simulation study. 10 Jan 2021. In: Cancer epidemiology. https://doi.org/10.1016/j.canep.2020.101881

Andersson, T. M-L., Rutherford, M. J., Myklebust, T. Å., Møller, B., Soerjomataram, I., Arnold, M., Bray, F., Maxwell Parkin, D., Sasieni, P., Bucher, O., De, P., Engholm, G., Gavin, A., Little, A., Porter, G., Ramanakumar, A. V., Saint-Jacques, N., Walsh, P. M., Woods, R. R. & Lambert, P. C.
Exploring the impact of cancer registry completeness on international cancer survival differences: a simulation study. 09 Dec 2020. In: British Journal of Cancer. https://doi.org/10.1186/s13063-021-05255-z

NICR Publications June 2020-June 2021 *(continued)*

Pilleron, S., Charvat, H., Araghi, M., Arnold, M., Fidler-Benaoudia, M. M., Bardot, A., Guren, M. G., Tervonen, H., Little, A., O'Connell, D. L., **Gavin, A.,** De, P., Aagaard Thomsen, L., Møller, B., Jackson, C., Bucher, O., Walsh, P. M., Vernon, S., Bray, F. & Soerjomataram, I.
Age disparities in stage-specific colon cancer survival across seven countries: an ICBP SURVMARK-2 population-based study. 02 Oct 2020. In: International Journal of Cancer. https://doi.org/10.1002/ijc.33326

Smith, L., Downing, A., Norman, P., Wright, P., Hounsome, L., Watson, E., Wagland, R., Selby, P., Kind, P., Donnelly, D., Butcher, H., Huws, D., McNair, E., **Gavin, A.** & Glaser, A. W.
Influence of deprivation and rurality on patient-reported outcomes of men living with and beyond prostate cancer diagnosis in the UK: a population-based study. 28 Sep 2020. In: Cancer epidemiology. https://doi.org/10.1016/j.canep.2020.101830

Collaço, N., Wagland, R., Alexis, O., **Gavin, A.,** Glaser, A. & Watson, E. K.
The experiences and needs of couples affected by prostate cancer aged 65 and under :a qualitative study. 24 Sep 2020. In: Journal of Cancer Survivorship. https://doi.org/10.1007/s11764-020-00936-1

Lu, L., **Gavin, A.,** Drummond, F. J. & Sharp, L.
Cumulative financial stress as a potential risk factor for cancer-related fatigue among prostate cancer survivors. 01 Aug 2020. In: Journal of Cancer Survivorship. https://doi.org/10.1007/s11764-020-00906-7

Twohig-Bennett, L., **Coleman, H. G.,** Cairnduff, V., McManus, D. T., Murray, L. J., **Gavin, A. T.** & Johnston, B. T.
Esophageal Columnar Metaplasia in Childhood: A Population-Based Case Series Analysis
18 Jul 2020. In: Digestive Diseases and Sciences. https://doi.org/10.1007/s10620-020-06462-5

Matheson, L., Nayoan, J., Rivas, C., Brett, J., Wright, P., Butcher, H., Jordan, P., **Gavin, A.,** Glaser, A., Mason, M., Wagland, R. & Watson, E.
Strategies for living well with hormone-responsive advanced prostate cancer—a qualitative exploration. 06 Jul 2020. In: Supportive Care in Cancer. https://doi.org/10.1007/s00520-020-05594-8

Northern Ireland Cancer Registry Group; **Donnelly, DW., Anderson, LA., Gavin, A.**
Cancer Incidence Projections in Northern Ireland to 2040. 01 Jul 2020, In: Cancer Epidemiology Biomarkers & Prevention. https://doi.org/10.1158/1055-9965.EPI-20-0098

Morgan, E., Soerjomataram, I., **Gavin, A. T.,** Rutherford, M. J., Gatenby, P., Bardot, A., Ferlay, J., Bucher, O., De, P., Engholm, G., Jackson, C., Kozie, S., Little, A., Møller, B., Shack, L., Tervonen, H., Thursfield, V., Vernon, S., Walsh, P. M., Woods, R. R. & 6 others.
International trends in oesophageal cancer survival by histological subtype between 1995 and 2014. 17 Jun 2020. In: Gut. http://dx.doi.org/10.1136/gutjnl-2020-321089

Staff News

New Staff

In June 2021 the Registry welcomed Simon O'Hare as the new Macmillan Statistician. Simon replaces Helen Mitchell who has moved to the NICR Team as Statistician.

A very warm and extended welcome back to Sean Morrison. Sean has returned from a one year secondment to continue his work with Prof Helen Coleman and Dr Victoria Cairnduff on the NI Barrett's register update. When he is not engrossed in reviewing thousands of pathology reports, Sean continues to provide vital clerical support to the NI Barrett's register and wider Cancer Epidemiology teams.

Sean's additional skills sets gained from his recent secondment are not going to waste though, and we are excited to more formally welcome Sean into the NI Cancer Registry staff where he will be supporting IT and data governance activities.

Congratulations

Congratulations to the Registry's Clinical Liaison Sinead and her husband Kevin on their marriage. Despite COVID and lock-downs Sinead and Kevin were able to have their wedding on their originally planned date, 11th December 2020 . We wish the new Mr and Mrs Hawkins *(left)* every good fortune in their married life together!

Staff News

CBE Award

The Registry wishes to congratulate Professor Roy Spence, former Chair of NICR Council, on his recent CBE award.

Secondment

Ashley Levickas, NICR TVO, is on secondment - currently until December 2021 - as a Research Assistant for the School of Pharmacy working in the LAMP lab performing COVID-19 asymptomatic testing for all of the special schools in Northern Ireland.

Farewell

The Registry said goodbye to Analyst Dr Tewodros Getachew in October 2020. We wish Tewodros every success in this next chapter of his life.

Paul Few, IT system analyst, left the Registry in December 2020. We wish Paul every success in his new job.

Dr Therese Kearney left the Registry in March 2021 to join the MOSIACC team in the Centre for Public Health, QUB. We wish Therese every success in her new role.

Staff News

Farewell

In May 2021 the Registry said a very sad goodbye to one of the longest serving members of Staff, Mr Colin Fox. Colin joined the Registry Team in 1994 to develop a Cancer Registration system and soon became a piece of the furniture. On Thursday 24th June staff were able to meet in Botanic Gardens to give Colin a proper farewell.

Colin will be sadly missed by all and we wish him every success in his new role with the Encompass team.

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